BEYOND THE END OR THE MEANS:

CO-THEORIZING ENGAGEMENT FOR HIV PROGRAMMING AND SERVICE PROVISION

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Abstract

Within health, community engagement is positioned as either a means, or an end. It is often framed as an apolitical, linear, and/or individualistic process, thus eschewing the relational or socio-structural factors that inform it. Although the rhetoric of engagement can be found across multiple policy, program and funding documents, the ways in which engagement is understood (or enacted) are rarely explored. As a 'fuzzy' concept, it regularly morphs across contexts, leading many – including those working in the HIV sector – to note that engagement is undertheorized. "Picturing Participation: Exploring Engagement in HIV Programming, Service Provision and Care" is a community-based participatory research project, co-led by a team of community members, staff and academic researchers. It uses case study design and photovoice to explore how stakeholders conceptualize engagement within and across different HIV organizational sites: an AIDS service organization, a youth HIV prevention program and a sub-acute HIV hospital. This dissertation is nested in this larger project; it contains several sole and co-authored elements, including: an introduction, a community-report that provides an overview of key project findings, three stand-alone manuscripts, poetry, photography and installations. The first co-authored manuscript explores how participants use of journey metaphors illustrates their understandings of engagement as relational, temporal, and informed by organizational contexts and stakeholder roles. In the second manuscript, I put youths' narratives of non-participation in conversation with decolonial and critical scholarship on the politics of refusal, neoliberalism, will, and the 'call to participate.' This reading demonstrates how not participating can be productively read as a self-determined form of resistance. The last two chapters explore what new conditions of possibility are created for (co)-theorizing engagement if engagement is approached as a 'beyond.' The third manuscript explores how my theoretical conceptions as a researcher/facilitator inevitably shaped the design and implementation of the methods used. I explore the methodological opportunities of bridging photovoice with site-specific installations, and working with the crafted-nature of images. The discussion proposes a new way of theorizing engagement as a dynamic, affective and pedagogical (and thus relational and ethical) process. It shares a researcher-produced installation as a site to reflect on the opportunities and tensions of doing collaborative, interdisciplinary doctoral work.

To the ones who are no longer with us:

lost
from this project
from our communities
from our families

dropped
not like tomatoes from the vine
but ripped –
these inequities

their refusal to listen
they talk, we die
too soon
too soon

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Glossary - Acronyms[1]

AIDS Service Organization	ASO
Community-based participatory research	CBPR
Greater Involvement of People living with HIV	GIPA
Meaningful Engagement of People living with HIV	MEPA
Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome	HIV/AIDS
Participatory Visual Methods	PVM
Two-spirit, lesbian, gay, trans, bi-sexual, queer	2SLGTBQ

Glossary - Key Terms

Community co-investigator	Refers to community members who were recruited to play an active role on the research team. These were official members of the research team. In health research co-investigators do not require academic affiliations.
Participants	Refers to research participants
Working group	Because of the size of the research team, we often divided into working groups to complete project related tasks. A smaller working group composed largely of community co-investigators, myself, and some staff representatives played a more active role in day-to-day project decisions.
Full research team	This refers to the full research team which included a variety of different people in different roles, including academic researchers, community representatives, and organizational staff who played an advisory role, where necessary.

[1] With the exception of PVM, these acronyms are often used regularly within the field.

Field Notes: A letter to my participants

To begin at the invisible beginning -- this song from your hands and mine -- what it means to arrive. To journey together.

I think back to what I did not yet know when I started this work, what I still do not yet know, what I may never know: what it means to do community-engaged work.

In a way, my writing, my research, and my teaching is a mucking about in what all of us do not yet know, and yet simultaneously know – what it means to share truths held deep in our bones, in our sinews, in our elbows, and in our hips with another who might listen. The shift in the room after a groan, or after sigh in recognition.

This work is a mucking about in a place of collective arrival: sitting around a table, across from a collection of photographs, a kit of objects, yet another hummus and vegetable plate. This table is a meeting place of embodied orientations and calculated decisions: why we string one set of words together in a room over another, each of us assessing whether or not the group will hold me, hold you, hold this loss, this hope,

this moment of contestation.

After so many months of writing, of mucking about, it always comes back to this: relationships. Our relationships with each other, and with ourselves, and with the land that we stand on. This thread seems to flow through my creative, personal, and professional life.

After so many years of forged glances; of "I wish I had known"; of emotional repair, of gratitude and mistakes; of failure; of loss; of joy, and surprise. After years of learning what I know and certainly don't know now. After years of learning that wisdom lies in an art room of a hospital, a community health centre, in a whisper through the firs, in a walk through (and sometimes out of) an agency door.

I cannot un-need you. We cannot un-need each other.

We are in this together, you and me. This reciprocity, this memory project, this co-construction of your truth and mine -- our bodies differentially marked by and in this process. And yet when I write, in *this* moment, it is difficult to discern where our story-lines stop and start. This photograph of loss: is it your story or mine?

I want to take a hammer to the saviour complex that is embedded in social work, education, and health -- to this idea of the 'helping profession'. Don't we help each other? Anyone who has worked in these fields long enough knows that these boundaries are not quite so simple. Even now – on this page - we are mashed together - like a seedy, strawberry banana milkshake placed incongruously in a set of field notes about arrival and research.

I don't know if you consented to this, but you changed me.

Perhaps this is why this work has un-hinged me. To do this work, we must be willing to put our ideas of who we are on the line, and to do so, we must do so with no guarantees, no program plans, no pre-scripted methodology to guide our way.[2] Relationships after all have no guarantee: they are human. They are messy, and complicated. They are unfavourable, and tested. They are supportive, and generative. And, they are always, remarkably, partially, true.

Thank you for trusting me with your words.

[2] This draws on the work of "pedagogy of solidarity" as explored by Gaztambide-Fernández (2012).

"We have come to our project by attending to our felt senses, by listening to our hunches…. [by] try[ing] things on, to say what feels like small things out loud and listen to the echoes. In this way, we engage collectively in restructuring our own realities. We engage together in reconstructing our own realities. We engage together in/toward self-determination and re-cognition."

Tuck et. al (2008), PAR praxes for now and future change, p. 60

Introduction

This dissertation explores ideas about engagement across the HIV sector. Parts of the dissertation were conducted collaboratively, and others were solo ventures. In both cases, this dissertation speaks to much of what Tuck et. al (2008) allude to in the introductory quote: attending to hunches, trying things on, feeling what it's like to say small things out loud, and listening to the echoes. This is a dissertation about self-determination, and reaching *towards.*

This introduction provides: 1) an overview of this dissertation that describes its format and how I arrived at this work; 2) a critical reading of the literature on engagement and participation as a larger field[1]; 3) an outline of my research paradigms, and theoretical frameworks; and 4) a brief description of my methods.

Summary

The dissertation is nested within a larger, externally-funded community-based participatory research (CBPR) project, "Picturing Participation: Exploring Engagement in HIV Programming, Service Provision and Care." The details of this project are discussed in-depth throughout. However, in summary, I co-led the development, funding application, project coordination, and partnership building for this project. I did so in partnership with a research team of academic

[1] In order to avoid repetition, some of the key literature is not mentioned in this chapter, but rather in chapters three, four and five.

researchers, program coordinators, directors and community members from three organizational sites: a sub-acute HIV hospital, a youth-led HIV prevention peer education program, and an AIDS Service Organization (ASO). Our workshops took place in Toronto (from the Mohawk word Tkaronto).

These three sites represent very different organizational contexts, with unique service and program mandates. Our project team included two representatives from each site (a staff member, and community member) who formed the inner circle that made decisions about research design, analysis, and dissemination. We also hired a peer researcher associated with one of the sites to help co-facilitate workshops. I worked closely with this group – in particular the community members associated with each site. They are referred to as community co-investigators throughout.[2] Other academic researchers on the team played an 'advisory' role.

Each site serves different communities living with and affected by HIV and operates with its own understandings of engagement, as shaped by various socio-political, historical and contextual factors. I had an in situ understanding of some of these distinct understandings prior to the study; I have been professionally involved with each of the sites in a variety of paid and/or volunteer roles since 2010. For example, over time I have been a project coordinator, front-line worker, research coordinator, or advisory board member at these sites. Many of these experiences involved leading, coordinating, or co-facilitating community-engaged projects. It was through observing the discursive and material differences around engagement at each site that the inspirational spark for this project was ignited. This flame was sustained through subsequent conversations with

[2] For community co-investigators, the decision to identify oneself by name is a highly-negotiated process. In presentations, websites, public documents (e.g., community report), and co-written articles (where they have shared ownerships over the product), these individuals were explicitly named as co-authors. However, for the purpose of this dissertation (a primarily academic output), they have only been named in places where they have given me explicit consent.

community members, and staff from partner organizations. I had pre-existing relationships (of varying depths) with many stakeholders – including community co-investigators, academic researchers, organizational staff, and some participants. These relationships are foundational to this work. I start with these relationships. I do so to be transparent about the processes through which this project came about. The relational element of engagement is a theoretical cornerstone to my work. It is also pragmatic. I could not (and would not) do this work alone.

The project follows a CBPR approach. CBPR is an approach to doing research where community members, or organizations are involved in all stages of research from design to dissemination (Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2008). Together, we used a case study design (Yin, 2003) and photovoice (Wang & Burris, 1997) to explore how different stakeholders understand engagement within and across three organizational sites providing HIV programming, service provision, or care. Photovoice is a method where participants take pictures to identify, discuss and analyze issues or ideas in their own communities. The larger objectives of the project were:

1. To use case study analysis and photovoice to explore how stakeholders (clients, peers, volunteers, service providers, clinicians, etc.) conceptualize community engagement processes within three different HIV programming or service delivery organizations.
2. To identify ethical, organizational or socio-political/historical issues that shape the context of HIV community engagement within and across different HIV organizational sites.
3. To create a series of community and academic resources on engagement in the context of HIV prevention, service delivery and care.

Although photovoice comprised a main component of this work, I was interested in carefully crafting and hybridizing our methods to be interactive, embodied, and pedagogical. As I will explore throughout, I intentionally intervened in the traditional photovoice method to: 1) align the method more squarely with the goals of CBPR and to 2) interrupt the "truth effect" of the image by working with participants to craft site-specific installations that represented themes at each of

the sites. Installations were not initially planned in the study, but emerged as a result of a facilitated process with participants who demanded that we present our work in different ways. This hybridization of methods is common in other forms of participatory research (see: Tuck et al., 2008), as well as qualitative research traditions that see research as a practice of montage (Denzin & Lincoln, 2011). In line with my CBPR approach and photovoice method, drawing on the work of Tuck et al. (2008), Herising (2005), and Sánchez (2009), I was also interested in co-theorizing with community members.

Dissertation Research Questions

My dissertation is nested within this larger project; it both overlaps with, and departs from some of these goals. My research questions ask:

1. Using case study analysis and photovoice, how do different stakeholders (clients, peers, volunteers, service providers, clinicians, etc.) conceptualize engagement processes *within* and *across* three different HIV programming or service-delivery organizations? How are these conceptions shaped by contextual or socio-political/historical factors *within* and *across* these sites?
2. When engaging different stakeholders from HIV community-based organizations in a participatory photography project, what new conditions of possibility are created for theorizing engagement? In other words, using my own role as a participatory visual methods researcher/facilitator and artist as a site for theorizing, how might this project offer new ways of thinking about engagement?
3. How might using photovoice to explore engagement contribute to methodological insights on the design and execution of future participatory visual methods projects?

I explore all three questions in different ways throughout. The careful sequencing, and analytic distinction in these questions is important. In her work on research as praxis, Lather (1986) advocates for research that demonstrates a commitment to reciprocity through designated opportunities to negotiate meaning and collaboratively build theory in projects. She suggests various ways of ensuring rigor in a post-positivist context where work is guided by a priori theory, while also being committed to open-ended, dialectical theory building. For Lather, the balance of rigor and co-theorizing can be achieved by careful sequential ordering of research questions (i.e.,

analytic distinctions); methods that allow for a continued probing of issues (i.e., meeting over time – like in photovoice); and self-disclosure on the part of the researcher.

As will be discussed later, it was important for me to distill how others understood engagement (question one) from my own theorizing (question two). This is not to say my own theorizing did not affect the data produced - quite the contrary. However, the analytic distinctions created an opportunity for me to be transparent about my own theoretical orientations (a priori theory) in shaping the work. Given the complexity of conducting collaborative work, I wanted to have an independent site to reflect on my own conceptions. I recognize that this project is not innocent. I spent three years of my doctoral work theorizing prior to collaboratively developing our project. This meant I arrived at this project with some theoretical positions already formed. I also had methodological and creative interests that were not taken up by the larger study objectives (e.g., question two and three).

Dissertation Format

My dissertation responds to these questions in the form of 6 chapters, 3 of which are stand-alone manuscripts fashioned for peer-review publication. Each manuscript speaks to a different audience. This is an important component of my interdisciplinary work. This format helped me navigate some of the complexities of doing collaborative work as part of a doctoral dissertation (for a deeper discussion of this issue, see "troubling the we" in the conclusion). It also allowed me to parse out collaborative and independent elements. The chapters are as follows:

1) *Introduction*: This chapter provides an outline for this dissertation, discusses the larger field of community engagement, and 'sets the stage' for the work that follows.
2) *Picturing Participation: Exploring Engagement in HIV Programming, Service Provision*

and Care. This co-authored community report highlights the seven themes that emerged from the larger CBPR study. Its primary aim is to provide a brief overview of findings to health practitioners and community members to facilitate deeper, more nuanced conversations about community engagement in their practice. It is not meant to be an academic output. Rather, its intended audience is much broader. Because this dissertation is nested within a larger CBPR project, including this report allows me to stay 'true' to some of the collective goals of this work. Accompanying this report is a brief description of how we arrived at these themes, and the report. The report has been published and widely disseminated.

3) *Journeying Together: A visual exploration of engagement in HIV programming and services* (Target journal: health): This co-authored article provides an in-depth visual and thematic analysis of one of the seven study themes. When participants were asked to photograph their understandings of engagement, they chose to depict their personal and organizational journeys. These visualizations followed particular visual metaphors that often aligned by site. Along with my co-authors, I compare and contrast each site's collective understandings, in order to illustrate how: 1) understandings of engagement are shaped by organizational context, and stakeholders' roles within them; and 2) the metaphor of journey may be a generative site to reflect on engagement. We conclude by reflecting on what the lens of 'journey' might enable for thinking about engagement as a dynamic and relational process. The audience for this manuscript is qualitative health researchers, and CBPR and health practitioners.

4) *"People give or take a lot to participate in things": Youth talk back – A case for non-participation* (Target journal: education). This sole-authored article provides an in-depth

analysis of another of the seven themes. When young people were asked to take photographs of engagement, they shared their challenges participating in youth programs. They also talked about not participating. I take inspiration from these conversations in order to tease out what a position of non-participation might offer for practitioners working with young people. Drawing on decolonial and feminist theory, the paper illustrates that young people have very sophisticated understandings of the material and discursive effects of the 'call the participation' in this neoliberal era. My audience is educators (working in community contexts), community developers, participatory researchers, and youth workers.

5) *Working with Photo-Installations and Metaphor: New Directions for Photovoice Research* (Target journal: Qualitative research methods). This sole-authored article provides an in-depth exploration of the project's methodology, and illustrates the potential of working with crafted images, and site-specific photo installations as a new avenue for photovoice research. In this article, I trace the impact of my pedagogical and theoretical fingerprints on the design of the photovoice workshops, and the larger study. My audience is participatory visual methods practitioners.
6) *Discussion:* The dissertation concludes with an-depth discussion of the theoretical and methodological contributions of this work. It includes commentary on the tensions of doing collaborative work as part of one's thesis. In this chapter, I put forward my own conceptualization of engagement as a dynamic, affective and pedagogical (and thus relational and ethical) process. Taken together, the dissertation demonstrates the need for a re-conceptualization of engagement as neither an end nor a means, but a beyond. This is a key contribution of this work.

7) *Creative Practice*: Interspersed between the chapters is a selection of poetry, and a (photo/video) installation I created to mark my own doctoral journey. As will be discussed throughout, I see the role of the facilitator (and their own investments) as central to understandings of community engagement. My creative practice is a way to trace some of these affective investments. This is not a separate chapter per-se, but I have listed it here to mark its place and contribution to the dissertation.

Because of the manuscript-based dissertation format, there is some inevitable repetition throughout. I have done my best to reduce repetition (where I can), and have carefully thought through how and where information has been presented. Last, to supplement this dissertation, I worked with my team to create an interactive photography exhibit; an online exhibit and website (https://pictureparticipation.wixsite.com/gallery); and several public presentations and workshops co-led with team members. These contributions are referenced throughout.

Literature Review: Unpacking Participation and Engagement

Community engagement is widely recognized as a cornerstone of ethical and community-responsive research and practice, especially within the field of community health (Hood, Brewer, Jackson, & Wewers, 2010; Minkler & Wallerstein, 2008; Wallerstein & Duran, 2010). In the 1980s, the language of community engagement, participation, and empowerment made its way into large scale health institutions such as the World Health Organization and the National Institutes of Health (Minkler, 2012). With the help of high-level international forums, the discourse of 'community engagement' can be found across international, national, and local contexts. While this is one 'origin' story, there are multiple points of departure for this review.

Public Participation and Social Movements

The history of community-based participatory research and participatory action research (a field that I draw on throughout) has historically been intertwined with social movements – in part due to its Freirean (1973, 2000) roots. Participatory practices were initiated, and largely developed by community organizers and social justice advocates in the global south. Many of these early projects can be traced to activists and scholars working in parts of Africa, India and Latin America in the 1970s (Fals-Borda & Rahman, 1991; Hall, 1996). Of course, this is not to say that public participation was born in the 1970's, but rather, it is during this time that the concept – as tied to community development and structural change – was first discursively mobilized.

One may also find other origin stories in prior social movements. For example, the civil rights movement in the 1950s-1960s was one of the largest social movements in history, with thousands of 'every-day', 'ordinary' people rising up to participate in marches, sit-ins and other public demonstrations. This movement was informed by understandings of public participation

that involved a shift from the individual to the collective, as best expressed through the transformative use of freedom songs (Reed, 2005). These songs often acted as a model for non-hierarchical, and intergenerational leadership. Black coalition leader and composer, Bernice Johnson Reagon argued that it was through freedom songs that many individuals found the power of community, as well as a spark for critical consciousness, and courage in the face of mounting violence, and inequity. Alternatively, as Cordell Reagon, the founding member of the Freedom Singers of the Student Nonviolent Coordinating Committee expressed, "the sound, the power of the community, was watching over you and keeping you safe" (qtd. in Reed, 2005, pp. 14, 26). The civil rights movement was also home to the radical thought of often under-recognized Black leaders like Ella Baker, whose view of group-centered leadership and relationship-building bears a striking resemblance to many of the chords of public participation addressed throughout this dissertation. As she argued: "I have always thought what is needed is the development of people who are interested not in being leaders, as much as developing leadership among other people" (qtd. in Payne, 1989, p. 892).

The civil rights movement had many meeting spaces – most notably, churches. Many meetings were also held at the Highlander Centre in Tennessee, which later became home to initial conversations about participatory research, popular education and community development in the 1970s (Brydon-Miller & Maguire, 2009; Cammarota & Fine, 2008; Lewis, Reason, & Bradbury, 2006). More locally, many of these conversations were sparked by the International Council for Adult Education's Participatory Research Project in 1977 – located in Toronto. Hall (1996) describes this project as one that was fundamentally connected with social movements. From establishing links with immigrant women factory workers, labour movements, Indigenous communities, and Latin American newcomers, these initial conversations about participatory

research were intricately rooted in concepts of collaboration that often extended beyond (and sometimes challenged) national borders.

For many, participation was about supporting the voices from the margins in *specific* projects and struggles. Fals-Borda and Rahman (1991) argue that the "basic ingredients" to participation involves "enabling oppressed groups and classes to acquire sufficient creative and transforming leverage as expressed in specific projects, acts and class struggles" (p. 4). They explained that the "essence" of participation involved breaking the subject/object binary – alluding, although not directly, to the legacy of Freire.[3] In other words, for Brazilian scholar Fals-Borda (who was credited with coining the term 'participatory research'), the goal of participation was always social transformation.

This history – as tied to social movements - is not always the 'origin' story that is found in many scholarly articles on community engagement. In teaching ENVS 3125 Popular Education for Social and Environmental Justice in 2016, I urged my students to think through participation politically. The course started with Freire and the revolutionary roots of participation in Latin America (Kane, 2001); and the work of the Highlander Center – including its role in the civil rights movement. We moved on to study popular education and participation as connected to prison abolition movements; youth-led peer education organizing(Switzer et al., 2016); Black Arts and Popular Education – a "process of collaboratively unearthing people's knowledges and critical reflections on issues in order to fight for liberation" (Mire & Kidane, 2015, p. 2); toolkits and participatory video projects created to raise up young Indigenous women's voices (Native Youth Sexual Health Network, 2011); and literacy projects with migrant farm workers. As some students

[3] Freire's work on deconstructing this subject/object binary, dialogic action, and conscientização (critical consciousness) has informed the tradition of participation for social change or community development – even if not explicitly referenced. I will return to Freire later.

moved towards the technocratic, I reminded them to always keep social and structural change at their finger-tips. I also professed the contradictions of the course – popular education was never meant to be taken up in the academy. A similar contradiction exists within this literature review.

This dissertation focuses on 'invited' forms of participation within engagement projects. (I will distill these terms shortly). In other words, I focus on engagement initiatives that are connected to the state, vis-a-vis community-based organizations, universities, hospitals or non-profit organizations. These invited forms may be informed by (but often depart from) many forms of popular participation. Under a neoliberal order (to be explored, and defined in greater depth in chapter four), participation often serves different ends. This is not to say that non-profit organizations cannot mobilize with and alongside social movements – only that this relationship is more complicated. From Idle No More, to Black Lives Matter, to youth staging high school walkouts over the sexual health curriculum, to harm reduction activists opening up pop-up overdose prevention sites, there are many examples of social movements that have gained material and human support through connections to non-profit organizations. In fact, one of the recommendations in our community report is that community-based organizations ought to connect with advocacy efforts happening outside their organizational walls (see: chapter two).

For this reason (among many), it is important that I start with the origins of social movements. I too must keep social change at my fingertips, just as I urge my students. These movements and traditions politically inform much of my work – even if not always explicitly stated. Below, I move on to discuss participation and engagement as elaborated in the community development and health literature. This may have a 'white-washing' effect on this review. I move between multiple fields in order to examine the (sometimes contradictory) discourses of participation and engagement in health, so I can later expand on, and in many cases, dismantle a

priori assumptions of the field. I see this practice, as focusing on both the center, and the margin – to allude to hooks (1984).

Community Engagement

According to Head (2007) – in sharp contrast to the above - the discourse and practice of community engagement can be found across three sectors: government, business and community (i.e., non-governmental organizations).[4] In in the community sector, understandings of engagement in non-government organizations have been largely motivated by principles of equity; greater voice and influence of those affected; and hope for improved conditions for disadvantaged groups. While motivations for engagement might vary (e.g., business vs. community development), what unites these sectors is vagueness of the term, engagement (Head, 2007). This dissertation focuses primarily on the community sector (more specifically, the HIV sector) and where it crosses with community-based participatory research, the academy.

The 'fuzziness' of community engagement has been noted by many (Barello, Graffigna, & Vegni, 2012; Hutcheson, 2014; Schulman, 2006). In his discussion of community engagement Head (2007) argues:

> The term 'community' is notoriously vague and value-laden. It is often a euphemistic term that glosses over the social, economic and cultural differentiation of localities or peoples. It often implies a (false and misleading) sense of identity, harmony, cooperation and inclusiveness. Its symbolic value explains much about its wide- spread usage in political discourse (p. 441).

The critique that the 'community' in 'community engagement' collapses difference is widely explored (Dempsey, 2010; Jewkes & Murcott, 1998; Van Deventer Iverson & James, 2014). Dominant framings of community engagement can construct a version of the self or community that is closed, or contained rather than one that is constantly in formation. Rather than viewing 'community' as a fixed social/economic/geographic entity, how might one acknowledge the

[4] Note that Head does not reference social movements or political organizing in his review.

multiple constitutions and interests that make up and form community through community engagement projects (Labonte, 1997)? For example, does a 'community' exist prior to a project, or is it merely called into being *through* a project? Either by design, or happenstance?

Montoya and Kent (2011) distinguish between community-based and community-driven efforts, arguing that the methods used and who is included (and excluded) will determine what 'counts' and what does not, in any participatory, dialogic process. Theses implicit and explicit questions around inclusion processes and methods are often left out of the literature. In harm reduction research with injection drug users, Higgs, Moore, and Aitken (2006) argue that when it comes to engagement, there is a disconnect between what practitioners and researchers say they do, and what they actually do in practice. Furthermore, a review by Paterson and Panessa (2008) found that despite the rhetoric of drug user participation in youth harm reduction programs and policies as an "ethical imperative," how youth engagement is conceptualized in the literature and implemented pragmatically is unclear. Literature rarely accounts for the nuances of engaging youth who have experienced marginalization (e.g., substance use, precarious housing, mental health challenges).[5] This has led many to review how organizations can better include the voices of people who use drugs in co-leading services and programs (Marshall, Dechman, Minichiello, Alcock, & Harris, 2015).There is clearly lots to be teased out regarding engagement in health.

And yet, to date, the majority of literature in health has focused on *individual effects* of engagement (Attree et al., 2011). A review of literature on patient engagement found that research tends to focus on the pragmatic impact of engagement on the client's health rather than on the

[5] While this article offers a useful starting point, I question what these authors mean by engagement as an "ethical imperative." Do they mean moral imperative? Importantly, their review 'measures' youth engagement across harm reduction initiatives, but they do not identify whether the reviewed study/initiative actually subscribed to a harm reduction philosophy. (Some do not). This suggests that they consider engagement to be an instrumental, apolitical means. Last, their review concludes that youth engagement in harm reduction initiatives is often predicated on a particular youth subject, without actually attending to the issue of difference in their review.

relational or organizational (contextual) processes that sustain it (Barello et al., 2012). Furthermore, despite the increasing recognition of the principle in medicine and nursing, how engagement is understood as a multi-dimensional process, and from the perspective of the 'patient' is unclear. As I read this literature, I was reminded of a poem by Puerto Rican and Jewish writer, Aurora Levins Morales (2013) who poetically narrates her experience of disability, health systems, and environmental racism. Her work challenges the reader to see the connection between bodies, and the land: "If I write about our bodies I am writing about the land and what has been done to it" (p. 7). In another poem, she writes: "Why do they call us 'the patient'. We are not patient. We endure" (p. 57).

The Canadian Institute for Health Research's new patient engagement framework defines patient engagement as the "meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation" (Canadian Institute of Health Research, 2014). But what does this look like in practice? What are the ideologies and conceptualizations underpinning it? How does it attend to the subjectivities of those 'being engaged?' Of those patients who are "not patient" ?

To continue with Aurora Levins Morales' (2013) poem:

> […] We are not patient. We are denied.
> Not medically necessary, they say, not proven.
> Feel free to appeal. We are experts at appealing,
> so we begin again, gathering documents, faxing releases,
> collecting letters and signatures,
> giving our numbers, all our numbers,
> to dozens of indifferent, underpaid clerks,
> stacking up evidence for the hearing,
> where we will declare as civilly as we can to the affronted panels
> that it is necessary that we breathe,
> sleep, digest, be eased of pain, have medicines
> and therapies and machines,
> and that we not be required to beg (p. 58).

Morales work provides a rich, compelling, and sometimes painful portrait of her experience "engaging" with medical institutions. This experience is one that is marked by her gender, race, and class. Based on her experiences, she puts forward her own conceptions of a community-based science that centers on healing justice. However, under CIHR's 'fuzzy' framework for patient engagement, her work is not only invisible, it gets erased.

Perhaps not surprisingly, this fuzziness is not an issue relegated to the field of health. Literature on youth engagement and engagement in community art is equally opaque (Hutcheson, 2014; Schulman, 2006). For example, Hutcheson (2014) argues that within the fields of community arts and creative place-making, the concept of engagement is equally "fuzzy":

> The intentions behind site-specific socially engaged projects range dramatically. They can be undertaken in order to improve the moral character of their participants (by, for example 'correcting' juvenile 'delinquency'). They can claim or hope to foster social integration. They can represent demands for systemic change or for a 'right to the city.' They can be undertaken in order to market a neighbourhood or site, making it more palatable to potential tourists or homeowners. [….] This is indeed a "fuzzy" field operating in a complex terrain (p.12).

Whether it's youth or patient engagement, or socially-engaged art, the context of any field will significantly influence how engagement is taken up discursively (Bess, Perkins, Cooper, & Jones, 2011). In other words, engagement will always be framed by the context of the field within which it is situated. Thus, in socially-engaged or community art, claims to what 'engagement' does (e.g., social integration) must also be read in line with the way in which discourses of the arts are often mobilized, uncritically, to meet particular ends (Gaztambide-Fernández, 2013). Similarly, as will be discussed in further detail in chapter four, and as explored in my other work (Switzer et al., 2016), conceptions of youth (e.g., as pre-adults not yet-developed, or romanticized leaders of tomorrow) and the history of the youth development sector has a strong influence on how youth engagement is understood.

To this end, I now turn to how engagement has been explored in the context of the HIV sector. While some of this history is covered in *Journeying Together* (chapter three), it is important to contextualize this history, as it frames the 'problem' or 'gap' this dissertation addresses.

The context of HIV Sector

In the late 1980s and early 1990's, at the same time that international forums were debating the values of social participation and community engagement, these principles were being enacted within the HIV movement through protests, in the forms of die-ins, conference sit-ins, and public art projects (McClelland, Guta, & Greenspan, 2018; Reed, 2005). In response to mass death and governmental and scientific inaction, HIV activists demanded inclusion in decision-making processes and 'a seat at the table.' As a result of these historical roots, GIPA/MEPA (the greater or meaningful involvement of people living with HIV) became ingrained into the first responses to the HIV epidemic (McClelland et al., 2018). As one of my community co-investigators, a long-term survivor of HIV passionately asserted, GIPA was instrumentalized, and remains essential to the HIV sector "because we're still alive."

This reference to "living not dying" alludes to the Denver Principles -- penned by early activists of the AIDS Coalition to Unleash Power, New York. The Denver Principles were a turning point in the history of AIDS activism, as people living with HIV demanded to be involved in public and scientific decisions, as a life-saving measure (Guta, Murray, & McClelland, 2011; Wright, 2013). As Guta et al. (2011) explain,

> perhaps most memorable in the Canadian context was the 1989 International AIDS Conference in Montreal, where 300 protestors forced their way into the auditorium waving banners declaring "SILENCE=DEATH"; the protesters then sat in the section reserved for VIP delegates and refused to leave. Intended as a "scientific" forum, conference organizers had previously ignored "community" interests in their high-level discussions (p. 16).

This important activism let to the development of AIDS Service Organizations (ASOs), and mechanisms for including people with lived experience in health programming and research more broadly (Epstein, 1995; Morolake, Stephens, & Welbourn, 2009).

Since then, the principles of GIPA/MEPA (Joint United Nations Programme on HIV/AIDS, 1999) and Nothing About Us Without Us (involvement of people who use drugs) (Jürgens, 2005) have been widely engrained, although not always employed, within the HIV response. In 2007, HIV activists and academics wrote the public report, *Living & Serving II*: *10 Years Later - The Involvement of People Living with HIV/AIDS in the Community AIDS Movement in Ontario* (E. Collins et al., 2007). This timely document called for AIDS Service Organizations to audit their internal GIPA practices, and for researchers to look outside ASOs to understand how a range of sites providing HIV services understand and implement GIPA. While research has been conducted on the perspectives of people living with HIV within ASOs and research teams, less work has been done exploring how HIV-related engagement is understood by diverse stakeholders within and across different organizational contexts providing HIV programming, or service provision -- such as community health centers and hospitals (E. Collins et al., 2007). For example, GIPA/MEPA - while important - does not account for the unique ethical, socio-political or contextual factors that impact youth engagement within peer-led HIV prevention and harm reduction projects, or patient engagement of people living with advanced-HIV who use drugs, and who are in hospital. Nor does it account for broader conditions of engagement that happen within community-based organizations – in other words, how people relate to each other, or the ways in which larger socio-structural factors or discourses shape the invitation to participate.

Almost a decade after the publication of *Living and Serving II*, while subsequent research has explored some of the opportunities and tensions, or facilitators and barriers of GIPA (Cain et

al., 2014; Carter et al., 2015; Li et al., 2015; Travers et al., 2008), this cross-sector view remains absent. Additionally, scholarship has overlooked how communities conceptualize or subjectively understand engagement beyond facilitators/barriers, harms/benefits, or impacts. There is no shortage of clinical studies focusing on the impact of engagement on people's viral load, and medical adherence (See: Kenya, Chida, Symes, & Shor-Posner, 2011; Marino, Simoni, & Silverstein, 2007). This individualistic approach is highly problematic, as it frames engagement as an apolitical process, thus eschewing any of the relational or structural implications. Furthermore, within an individual, behaviorist frame, what forms of participation get recognized as legitimate? Which origin stories get held up, and promoted?

For example, in Che Gossett's (2014) chapter, *We will not rest in peace: AIDS activism, black radicalism, queer and/or trans resistance*, they argue for the visibility of Black, queer, and trans prison abolition movements within the larger history of HIV activism. They contend that the "war on drugs – a moral, racialized, classed and police-militarized enterprise – intensified and escalated the AIDS epidemic through zero tolerance policies, mandatory minimum sentences, and by creating unsafe and vulnerable conditions for injection drug users (p.35)." They look to the work of ACT UP members Gregory Smith and Kiyoshi Kuromiya, or incarcerated AIDS activists David Gilbert (who co-founded an HIV peer education program) to illustrate the connections between early AIDS activism and anti-prison organizing. These early forms of resistance were central to the movement, and yet, under a biomedical frame, they are rarely held up as historical examples of participation within the HIV sector. As will be alluded to later, this invisibility also speaks to erasure of Black and Brown bodies in the public history of HIV organizing (Wilson, Flicker, Restoule, & Furman, 2016).

Alternatively, in their article, *Global AIDS Governance, Biofascism, and the Difficult Freedom of Expression,* Guta et al. (2011) narrate an experience of an HIV activist being formally expelled from the 2010 International AIDS Conference (and future conferences) for staging a protest. This protest included postering the Canadian Booth with the Vienna Declaration, as a way to reveal the Harper governments' hypocrisy, and the government's refusal to acknowledge harm reduction as a life-saving measure. The activist's violent expulsion from the conference is contrasted with the bio-medicalizing discourses of the conference, and the keynote offered by former U.S. president Bill Clinton, who shallowly references the work of those on the ground in fighting the epidemic. As more politicians talk, and more activists are expelled, the more individuals die from red tape. In a field where popular participation is often heralded as part of its history, this expulsion is telling.

This has led some scholars, to emphasize that participation and engagement within the HIV sector is largely under-theorized, especially as it relates to structural forms of power. As McClelland et al. (2018) argue, despite the frequency of appeals to principles of engagement within the sector,

> GIPA is often not interrogated and assumed to be unchanged, politically neutral, and both necessary and beneficial, without much discussion or debate. The underlying assumption here being that if international declarations and community-based organizational policies on GIPA were realized, social problems that are reproduced in community-based organizations, interventions and research projects would be resolved (p.5).

This under-theorization is not just a problem for scholars. An unsophisticated, or shallow understanding of engagement may lead to tokenistic attempts at inclusion, or consultation processes that merely reaffirm the status quo. It may also lead to engagement processes that are not tailored to particular communities living with and affected by HIV or different organizational contexts. For example, despite the 1994 Paris Declaration's acknowledgment that there is no one-

size fits all model for GIPA (Joint United Nations Programme on HIV/AIDS, 1999), the complexities and nuances of engagement processes across different contexts is rarely accounted for, or explored. It is for this reason, among many, that this dissertation looks beyond the discourse of GIPA/MEPA and takes up the concept of engagement more broadly.

In closing, this wider history, and the prominence of 'engagement' across the sector makes it a generative site for conceptual work on engagement. Many stakeholders within the Canadian HIV sector have spent considerable time thinking about how to meaningfully, feasibly, and sustainably include people with lived experience in organizational programming or change (Cain et al., 2014; Carter et al., 2015; Flicker, 2008; Guta, Flicker, & Roche, 2013; Travers et al., 2008). Ontario has the highest number of people living with HIV in the country (Public Health Agency of Canada, 2014). Within the province, Toronto has the highest number of new diagnoses, as well people currently living with HIV (Wilton, Liu, Sullivan, Sider, & Kroch, 2016). This translates into a sizable HIV sector with many different types of programming, and prevention initiatives. Furthermore, as a virus, HIV infection often plays out along axes of systemic discrimination (i.e., social determinants of health). While HIV has become a chronic infection (for some), those experiencing intersecting forms of oppression are most likely to be disproportionately affected and rendered ill by the epidemic (Public Health Agency of Canada, 2014). Combined with unique issues of stigma (Mahajan et al., 2008; Parker & Aggleton, 2003), this makes engagement with people living with, and affected by HIV more socially and ethically complex than many other health issues.

Current Models and Definitions

In this dissertation, I refer to both participation and engagement. In the literature, there is often slipperiness in how these terms are employed. Many articles I reviewed often conflated

participant retention with engagement, seeing numbers as a *fait accomplit*, despite the fact that participation and engagement are different processes (Fox et al., 2010; Schulman, 2006). Similar to Schulman (2006), I understand participation as being a part of engagement. In simple terms, participation is the act of taking part, or act of participating. *It is the doing, or the action.* In contrast, I understand engagement as encompassing participation, and many other elements: the discourses that surround participatory processes, participant's subjective understandings of both participation and engagement, the ways in which participatory projects are facilitated, and the way in which community engagement projects get mobilized for particular ends. Community engagement projects are often facilitated in, and tied to state-institutions (e.g., health centers, non-governmental organizations, universities). The language of community engagement can be mobilized in policy, programming, or funding documents. If participation is the individual action, engagement is the larger package.

In the scholarly and grey literature, engagement is usually framed as either an end (a community was engaged) or an instrumentalized means (we engaged a community in order to). Many toolkits define engagement using a definition from the Centre for Disease Control, where engagement is defined as a means of working with communities to change both individual behaviour, and policies, programs or practices. Here, community engagement is the:

> process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It is a powerful *vehicle* for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and *serve as catalysts* for changing policies, programs, and practices (Clinical and translational science awards consortium community engagement key function committee taskforce, 2011, p. 7 italics mine).

Community engagement may also be framed as an end. For example, Pancer, Rose-Krasnor, and Loiselle (2002) view [youth] engagement as "the meaningful participation and sustained

involvement of a young person *in an activity* that has a focus *outside* himself or herself" (emphasis mine, p. 47). As an end, engagement is framed to bring about a state of change. This end is positioned through individual, and technocratic properties (i.e., a set of activities). Sometimes, engagement is defined as both an end and a means. The Canadian Institute for Health Research's *Citizen Engagement Handbook* defines engagement as "the meaningful involvement of individual citizens in policy or program development. To put it simply, citizens are "engaged" when they play an active role in defining issues, considering solutions, and identifying resources or priorities for action (n.d., p. 5)." While engagement as a means is implied in this definition, their concept of engagement follows a linear trajectory, where it is positioned as a fixed state, or ends. Hence, engagement rather circularly, becomes the effect of engagement. This is affirmed by CIHR's continuum of engagement modelled after the International Association for Public Participation (2007) spectrum which moves from listening, to informing to discussion, to dialogue, to collaboration.

This participation spectrum is one of three common participation typologies frequently cited in community engagement literature and toolkits. They are listed in figure 1-2, in chronological order: 1) Arnstein's (1969) ladder of participation; 2) Roger's Hart's ladder (1997, 2008) (adapted from Arnstein) of shared decision-making with children and young people. The third typology, the International Association for Public Participation's (2007/2014) Spectrum of Public Participation is not displayed.[6] The most updated International Association for Public Participation (2014) spectrum denotes 5 stages of participation that are visualized as a linear process: inform, consult, involve, collaborate, and empower. Each stage is broken into two parts that contains a "public participation goal" (e.g., to consult – "to obtain public feedback on analysis,

[6] This typology is copyrighted, and so not displayed in the figure below.

alternatives and/or decisions") and a "promise to the public" (e.g., to consult – "we will keep you informed, listen, and acknowledge your concerns and aspirations, and provide feedback on how public input influenced the decision").

I will discuss these typologies in greater detail in chapter four, in *Youth Talk Back*, and in chapter six, where I explore their relationship to settler-colonial theories of change. However, in summary, the typologies present a linear framework for thinking through participation by illustrating either 1) the 'levels' of participation (i.e., what kind of participation or shared decision-making, as in Arnstein and Hart); or 2) the 'types' or channels of participation (e.g., informing, discussion, collaboration) (International Association for Public Participation). They make no reference to power, or the processes through which participation is enacted, invited, or facilitated, and instead frame participation as an unquestioned and neutral 'good' (Cornwall, 2008; Tritter & McCallum, 2006).

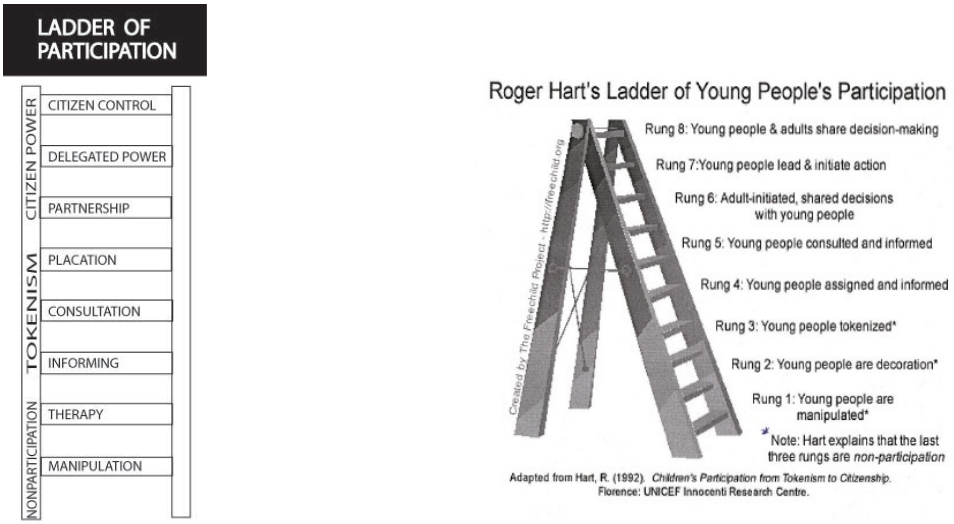

Figure 1-2 (left to right) : Arnstein (1969): Ladder of Citizen Engagement; Hart (1997): Children's Participation from Tokenism to Citizenship

Note that these typologies prioritize some forms of participation over others. They do not mention self-mobilization, and present non-participation as negative (or missing). It is telling that White (1996)'s typology – which focuses on what participation means to the individual and the organization - is rarely referenced. White's typology focuses on nominal, instrumental, representative, and transformative forms of participation. It also recognizes that participation can either entrench, reproduce, or subvert power structures. While she critiques instrumental forms of participation as a means (especially those conducted via efficiency or cost-saving narratives), this typology still falls into the trap of seeing engagement as a fixed end. Furthermore, as discussed later, participatory processes do not always fall into the dichotomy of either reproduction or subversion. These processes may entrench and subvert power-relations simultaneously.

For example, in some cases the rhetoric of community engagement may be at odds with the realities and political tensions of HIV CBPR. By focusing on "community needs" and community "relevance," formalized engagement structures in CBPR may unintentionally legitimate (unwanted) access to communities that may be otherwise inaccessible (Guta et al., 2014). Flattened conceptions of community, and a depoliticized approach to engagement may also exasperate community/academic tensions (Dempsey, 2010). Alternatively, in another study on CBPR and governmentality, Guta et al. (2013) explain how CBPR practitioners often spoke to the benefits of peer research (a mechanism for community engagement) through self-improvement narratives of crime reduction, and improved personal hygiene. Using a Foucauldian lens, they argue that the discourse of community engagement may function as a way to surveil communities – especially when it comes to CBPR with those who already marginalized. There are many overlaps between peer research in CBPR and peer work in the HIV sector.

Such complexities are missing from these often-cited participation typologies. It is telling that these typologies have been used so widely and with very little modification across the community health and research sector. Interestingly, these typologies were designed to describe participation, *not* engagement. This may be one reason that there is so much slippage between terms, and such 'fuzziness' in how engagement is understood and deployed. Because of the way in which these terms are used interchangeably, and because I see participation as a part of engagement, I conclude this literature review by outlining some of the critical scholarship on participation below.

The field of participation

Compared to literature on engagement, scholarship on participation is vast. The romanticization of participation has been noted across a broad base of fields from contemporary art (Bishop, 2012) to international development (Cooke & Kothari, 2001; Leal, 2007) to community-based participatory research (Guta et al., 2013), critical youth studies (Dhillon, 2017; Kwon, 2013; Tuck, 2013) and in some rare cases, community health (Chiu, 2008). Similar to engagement, participation has been widely recognized as a contested concept, operating as a floating signifier that shifts and morphs across different discursive contexts (Jenkins & Carpentier, 2013). It is an "infinitely malleable concept." (Cornwall, 2008, p. 269). This led participation scholars to argue that the field needed more 'clarity through specificity' (Cohen & Uphoff, 2011; Cornwall, 2008). "Participation has a long and checkered history" to which the concept has been mobilized to different ends (Cornwall, 2008, p. 281). Figure 3 illustrates the some of the contributions of this scholarship, as relevant to the study of engagement in the HIV sector.[7]

[7] Excluded from this discussion are philosophical explorations of participation (e.g., Jen-Luc Nancy or Barthes in Bishop (2006)); or forms of civic participation, such as participatory governance (Gaventa, 2004). These areas are related to, but outside the scope of this dissertation which focuses on invited forms of participation within community-based health organizations.

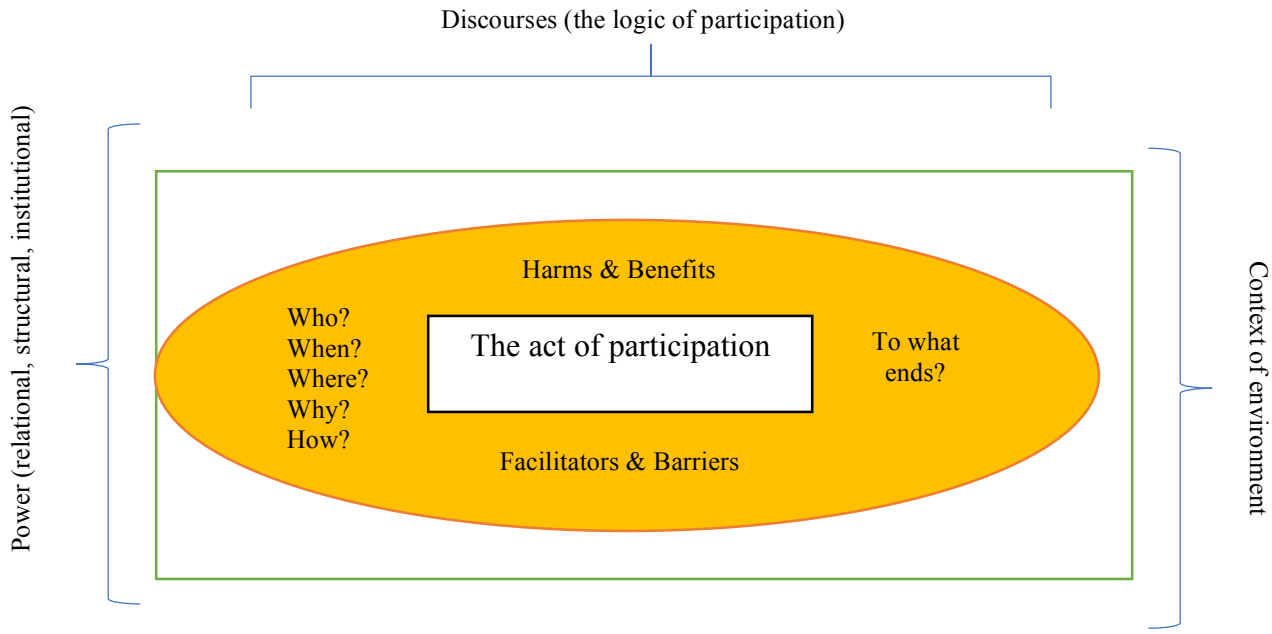

Figure 3 - Participation in community development (current areas of research)

First, participation is not a single phenomenon. The context of the environment (i.e, organization or institution) will always shape how participation is understood or mobilized (Bess, Prilleltensky, Perkins, & Collins, 2009; Cornwall, 2004, 2008; Moose, 2001). Any conversation or study of participation without its context will deem the concept meaningless.

Second the study of participation often begins with the action. I have been inspired by the critical scholarship of Cohen and Uphoff (2011), Cornwall (2008), and Chiu (2008), who have tackled the romanticization of participation in community development contexts by teasing out its elements, and usages. Questions of who participates; why; where; to what ends; and through what channels, processes or avenues are central (Cornwall, 2008). In the health sector, many of these 'who, why, what, where and how' questions have been addressed by studies or reports on facilitators/barriers or harms/benefits as referenced throughout. This is one area of scholarship in which the HIV and harm reduction literature has explored in great detail (see: chapter three,

Journeying Together). However, while these questions form the building-blocks of participation, they do not always get to the issue of power. As Belle-Isle (2016) argues, "While it is useful to examine such barriers and facilitators to participation, simply bringing representatives from marginalized communities to the table does not in itself imply [the] transformation of inequitable power relations, nor does it get to the core" of what shifting decision-making processes with communities really means (p.6).

Within the HIV 'community', there are many microcosms of power at play (e.g., racism, classism, stigma against drug-users) that impact both the act of participation (i.e., the who, what, how, etc.) but also larger discourses of participation. These discourses of participation are deeply steeped in, and connected to systems of domination such as neoliberalism, white supremacy, and settler-colonialism. For example, Wilson et al. (2016) speak to how the over-arching narrative of popular participation in HIV activism – framed as being publically led by gay, white men - has erased the voices and labour of Black and Indigenous people living, and affected with HIV who have been involved in resistance efforts since the 1980s. Alternatively, as Guta et al. (2011) and Gossett (2014) recount, within the larger HIV response, some forms of participation – such as public protest critiquing the state - are deemed less acceptable than others. Who is the presumed subject in participatory processes?

If we are to return to Fals-Borda and Rahman's (1991) early work, participation must not be seen as mere technique, but rather, as a means for re-distributing power-relations. I have drawn inspiration from participatory visual methods, and community arts scholars who have called on practitioners and researchers to ask critical questions of participation, such as 'to what ends?' (Barndt, 2004; Ford-Smith, 2001; Low, Brushwood Rose, Salvio, & Palacios, 2012; Milne, 2016). I have also been influenced by the scholarship of feminist participatory action researchers who

understand participation as connected to intersectional understandings of power; reflexivity; and people's every day, embodied experiences (Lykes & Hershberg, 2012). These particular understandings can originally be attributed to feminist scholars of colour such as bell hooks (1984, 1994), Patricia Hill Collins (2000), and Kimberly Crenshaw (1991). Collectively, this scholarship illustrates that far from being a neutral process, participation can be adopted to many different ends, and any discussion of participation must also take up issues of relational and institutional power. Participation is not a panacea. As Leal (2007) argues, on the global stage, participation has often been used as a buzzword, used to justify actions that perpetuate structural inequity. There have been many promises made to alleviate poverty in the name of participation, but with no commitment to look at the structures which produce it. "Politically ambiguous and definitionally vague, participation has historically been used both to enable ordinary people to gain agency and as a means of maintaining relations of rule." (p. 75).

In this vein, recent scholars (Dhillon, 2017; Guta et al., 2013; Kwon, 2013) have begun questioning the discursive effect of participation – in particular, the role of participation as another neoliberal strategy of surveillance and control, even when carried out within the rhetoric of social justice or collaborative knowledge production. In figure 4, this is scholarship is referred to as the "logics of participation." As these scholars describe, through neoliberal logics, participatory initiatives often put the burden of responsibility back onto individuals and communities and take attention away from the importance of larger state responses to inequity. The logics of participation and engagement are also implicated in, and informed by the project of settler-colonialism. For example, Dhillon (2017) describes how participatory projects with Indigenous youth use the rhetoric of participation to offer a shallow view of "reciprocity." Participation becomes a shiny object, meant to distract from the ongoing colonial dispossession of land. Here, participatory

processes may in fact may replicate the settler-colonial state rather than subverting it. Some of this literature has been applied to critically investigating the role of participation within the HIV sector, as referenced above (See: Guta et al., 2016; McClelland et al., 2018). I will return to and expand on this scholarship in chapter four, *Youth Talk Back,* and chapter six, my discussion.

What do we make of these critiques? I believe there is promise in working 'within' systems as we work against and beyond them. In fact, I see the inclusion of people with lived experience into programs, and organizations as an important step in addressing power inequities within the field of community health. And, as outlined in the following dissertation chapters, there are many opportunities that participation and community engagement engenders.

Tuck (2013) distinguishes between different types of participation, albeit in a very different way than the typologies referenced above [figure 1-3]. As she argues, shallow participation involves

> volunteering for a few hours of community service, voting in government elections, answering questions in a focus group or survey […] These activities are examples of shallow participation not because they are not worthwhile, but because they invite people to take part in something very defined and determined ways […] The possibilities for change are somewhat limited by the parameters set by others in shallow participation, and participants, knowing this, can be reluctant to pitch in […] Deep participation, by contrast, invites people to help define the scope of discussion, the rules of engagement, and the structure of relationships (p. 11).

What are the ways communities are *already* conceptualizing and re-imagining engagement in the HIV sector? How might new conceptualizations push us all to re-consider the "rules of engagement, and the structure of [our] relationships?" As scholars and practitioners, we must carefully attune ourselves to many of the questions raised above, and throughout this dissertation. We must carefully probe what is happening and why. But, we must also remain attune to the possibilities. I will return to, and build on this topic in my final discussion.

On co-theorizing[8]**:**

to realize, to re-make,
a conversation with,
rather than to:
the feeling of words
on our tongues,
in our elbows,
in our knee caps,
formed and informed
by our gut,
by the ground,
this land: a silent rumble
this you, and me
these sparks of
connection,
these chasms,
oh, these chasms
don't forget who
you roll with,
don't forget
why you are here.

[8] I am indebted to, and inspired by presentations (and conversations) with Timothy San Pedro, and Verónica Vélez during the "Indigenous and Decolonizing Studies in Education: A One Day Conference for Writers and Aspiring Writers" at OISE, University of Toronto in 2016. I attended this conference after having submitted the proposal for this dissertation, and two months prior to beginning field work. I had just published a collaboratively written book chapter with young people from Empower, and it was getting picked up by many unexpected fields (Switzer et al., 2016). It was an important juncture. Their presentations *Practice what we teach: Centering relationships in writing and decolonizing* (San Pedro) and *The Political and Spiritual Project of Writing Collectively (*Vélez) informed a draft version of this poem – scribed in the margins of a notebook. Both presentations inspired me to see me writing as a spiritual, political, relational and collaborative project. Their words (and work) gave me the strength to center the relationships I had cultivated within the communities I work within at the heart of this dissertation.

Methodology

"Amidst its provocations, what does this art make possible?"

Dunlop (2004), Scar tissue, testimony, beauty: Notebooks on theory, p. 95

Research Approach: Community-Based Participatory Research (CBPR)

My methodological approach responds to the call for researchers to move away from deficit-based research, and towards approaches that focus on the strengths and resilience of communities (Tuck, 2009). Tuck (2009) challenges well-intended research practices that attempt to leverage resources for marginalized communities by exploring larger socio-structural factors that put these very communities at disadvantage, and in doing so, reinforce one-dimensional notions of the community as hopeless, or ruined. This is "research that operates, even benevolently from a theory of change that establishes harm or injury in order to achieve reparation" (p.143). I wanted to work against research practices that only position the communities I work with as marginal. In response, this project has been designed so that I can work with communities to collectively co-theorize about the different ways stakeholders in the HIV sector conceptualize engagement. This does not mean that in this dissertation I ignore socio-structural factors. Instead, I speak to these factors as embedded in relation to larger discourses and institutions.

I take inspiration from Tuck and her co-authors (2009; 2008), and selected a research approach that centralizes collaborative knowledge production: community-based participatory research. CBPR is as "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each bring" (Minkler, 2012, p. p.4). The principles of CBPR include: ensuring the relevance of research questions to affected communities; engaging communities and community organizations as active research partners; building capacities and skills among research partners and community members; attending to

issues of power; and ensuring that data are used to affect social change (Minkler & Wallerstein, 2008).

While I ground my work in CBPR (in part due to scholarship within CBPR on participation, and CBPR's links to participatory HIV research, and funding streams), I am theoretically and politically aligned with the definition of participatory action research (PAR) provided by Tuck et al. (2008). Tuck et. al, understand PAR as politic – with strong links to the *who* and *how* of research. They understand PAR as "an embedded and out-loud critique of colonization, racism, misogyny, homophobia and heterosexism, classism, and xenophobia in our society, in our research sites, amongst our research collective, and within the larger and historical research community—rather than a fixed set of methods" (p. 51). This definition strikes a strong chord with the political values I bring to my work.

While I think it is possible to study engagement and participation outside of a participatory model, my interest in understanding the various ways different stakeholders conceptualize engagement and my ongoing relationships with HIV community-based organizations, make CBPR a wise research approach. Given my interest in learning from and alongside different stakeholders involved in HIV programming, and service-provision, it furthers my research aims to include and build on the skill-sets of these very stakeholders in the research process. After all, front-line organizations (and community members working within them) have a rich history incorporating GIPA and Nothing About Us Without Us principles into practice. As such, they often have sophisticated understandings of the complex contextual and socio-political issues related to engagement. This is what Sánchez (2009) refers to, drawing on Aurora Levins Morales, as "homemade theory" in participatory research. "Homemade theory" relates to early work by Fals-Borda and Rahman (1991) who argue: "through the actual experience of something we intuitively

apprehend its essence […] This combination of experience and commitment allows one to see for whom such knowledge is intended" – in this case, the communities themselves (p.4) When combined with a careful attention to my own role as facilitator and researcher, this collective lens on the research brings both theoretical and methodological insight. CBPR also aligns with my theoretical framework: praxis-oriented feminist research and participatory paradigms.

Qualitative Research: Constructivist and Participatory Paradigms

This dissertation is guided by both participatory and interpretive constructivist paradigms, within a larger tradition of qualitative research. According to Creswell (2003):

> a *qualitative* approach is one in which the inquirer often makes knowledge claims based primarily on constructivist perspectives (i.e., the multiple meanings of individual experiences, meanings socially and historically constructed. with an intent of developing a theory or pattern) or advocacy/participatory perspectives (i.e., political, issue-oriented, collaborative. or change oriented) or both. […] The researcher collects open-ended, emerging data with the primary intent of developing themes from the data (p. 18)

In interpretive-constructivist paradigms, reality is seen as multiple, shifting, and co-constructed (in contrast to post-positivist understandings of single, universal truths). Within this paradigm, knowledge is produced in relationship between researcher and participant, and heavily influenced by the socio-political, and historical context in which the participant is situated, the design of the study, and the researcher's influence. Thus, methods often employed within constructivist approaches are interested in the search for meaning and understanding, as it unfolds overtime. The researcher is seen as a co-creator of knowledge, and who comes to the project with their own theoretical understandings (Lincoln, Lynham, & Guba, 2011). A constructivist paradigm is relevant to my work because I am very interested in: 1) the subjective meanings and understandings that stakeholders bring to engagement projects; 2) how these understandings are shaped by organizational contexts; and 3) using these meanings and understandings to help me

further develop, or tease out my own theoretical understandings of engagement. In this paradigm, meanings are also directed towards objects or things (e.g., photographs) and can be seen as forged through discussion and interaction (Lincoln et al., 2011).

Where a constructivist paradigm differs from a participatory approach is that it does not necessarily see the goal of the research as invested in advancing a social change agenda, nor does it assume that participants will be concretely involved in actively, co-constructing knowledge through involvement in research design, analysis, etc. It is for this reason that I employ both paradigmatic approaches in my work. An emancipatory/participatory paradigm, according to Creswell (2003) operates from the following assumptions:

1) Research is dialectical and focused on bringing about change in institutional or social practices. Within this, researchers explicitly advance an action agenda.
2) Research begins with an important issue – in this case, engagement, or the importance of elevating the voices of people with lived experience in HIV programs and service delivery
3) The research process has emancipatory aims
4) Research is both practical and collaborative because it is conducted with people, rather than on or for people. To this end, research involves participants in shaping the design, analysis or dissemination of the research.

This paradigm is intricately connected to (and born out of) the work of Freire (1973, 2000) and Fals-Borda and Rahman (1991) who are addressed throughout this chapter. Creswell (2003) argues that even within these paradigms, researchers ought to further identify theoretical orientations for conducting their work. To this end, I turn to my theoretical frameworks below.

Theoretical Frameworks: Reading Sideways and Across

I intentionally borrow from a broad range of disciplines: education, community health, development, political science, social work, geography, and contemporary art, to construct my theoretical framework. I see my theoretical framework as intentionally interdisciplinary. I draw on interdisciplinary reading practices as a form of "promiscuous reading" (Heckert, 2010) or to quote

Ahmed (2014), as a process of reading "sideways and across, thus creating a different angle on what is being reproduced" (p. 15).

I see this interdisciplinary process as a queer approach, drawing on the metaphor of the fold or the hinge – as identified by my installation work. In conversation with Sandoval (2000), Jones and Adams (2010) argue that we may want to reflect on the role of the hinge and differential methodology: "[T]he hinge asks us to align what may seem divided perspectives – without forgetting their differences of their purposeful movements – in order to 'puncture through the everyday narratives that ties us to social time and space, to the descriptions, recitals and plots that dull and order our senses' " (p. 201). This interdisciplinary approach is also pragmatic: working at the intersections of community arts, education and health, I have no choice but to borrow, assemble, and bend into the folds of different disciplines. I resonate with the work of García Canclini (2014) who describes this interdisciplinary practice as "acting in the interstices" in which one borrows and translates concepts across different fields to accomplish their aims. Like Canclini, I see these interstices or folds as sites of possibility: "In order to produce non-metaphoric questions, the research carried out in each field must articulate with the questions posed in other fields" (p.14). It is also in this movement, where concepts have the potential to travel and where "inventions of cognitive openings or networks" (García Canclini, 2014, p. 77) can be formed.

At the crux of this interdisciplinary work is an attention to feminist, praxis-oriented research. Methodologically, critical feminist theory is congruent with my focus on co-theorizing, and knowledge as co-constructed, as discussed throughout (Hesse-Biber, 2013; Lykes & Hershberg, 2012). Central to a feminist understanding of co-theorizing is: 1) praxis; 2) an attention to multiple forms of *situated* knowledge (and its relationship to larger structures); and 3) a focus on possibility.

I define praxis in the tradition of Freire (1973, 2000), where praxis is considered a cyclical action of "reflection and action upon the world in order to transform it." (2000, p. 51).[9] This is connected to interdependence, of being in "a world of relations … a presence which is a *being with*" (Freire, 1973, p. 99 italics original). Of course, Freire's work does not exist without critique. Drawing on work by Bower, Grande (2015) argues that Freire's focus on human liberation can be seen as anthropocentric in its approach – particularly with respect to human/nature binary, and as such, is at odds with decolonizing efforts. She also suggests that the continual focus on critical consciousness and re-creation might downplay the importance of tradition and intergenerational knowledge. Freire's work has also been critiqued for adopting a phallocentric approach to the human, and implying that power relations might be shattered if one only develops a critical consciousness (hooks, 1994; Lykes & Hershberg, 2012). I agree with these critiques on gender, intergenerational knowledge, and the human/nature binary – preferring to see liberation as tied to intergenerational relationships between humans, non-humans, and the land. However, I disagree with Lykes & Hershberg's assertion that Freire does not see material power. Drawing on hooks (1994), I appreciate Freire's analysis, seeing the potential of his work "even if it is flawed" (p. 50).

This critical feminist framework also draws on the importance of multiple, and situated knowledges, as advocated through Black Feminist epistemologies, and scholars such as Patricia Hill Collins (2000) and hooks (1984, 1990, 1994). I have always been drawn to the work of feminist theorists – many of whom have been feminist theorists of colour, and/or queer feminist theorists theorizing at the intersections of theory, practice, personal experience, and struggle. Many of the theorists I cite in my work, I turn to as one turns to old friends (Ahmed, 2015). In connecting the dots between the personal and political, theory can help individuals make sense of their place

[9] Freire is also considered a key theorist, alongside Marx, in advancing a participatory/emancipatory paradigm as discussed above.

in the world (hooks, 1990). Many of these theorists have helped me make sense of my own place – as a white, cis-gendered, queer woman and settler. These theorists have also helped me draw connections between my own episodic experiences with disability, and the work that I do. This is often on-going work. As Saukko (2005) questions, "How can one be true to lived experience and at the same time, criticize the discourses that form the very stuff out of which our lived realities are made of?" (p.343). I am grateful to these theorists, and to friends, partners, colleagues, and committee members who have challenged me in this regard.

Thus, although I acknowledge that "[t]heory is not inherently healing, liberatory or revolutionary," I take hope in the role of theory for envisioning new possibilities and new ways of being (Ahmed, 2014, p. 10). To continue with Ahmed, theory "fulfills this function only when we ask that it do so and direct our theorizing towards the end" (Ahmed, 2014, p. 10). This connects well with the work of Fals-Borda and Rahman (1991) who insist that participatory processes must maintain a constant commitment to action. In directing this theorizing, critical feminist theory asks that as scholars, we connect the dots between relationships, structures, and our own situated role within them.

For example, Tuck and her colleagues (2009; 2012; 2014a) writing has challenged me to think differently about my work in terms of its implications for thinking through the discursive and material practices of settler-colonialism and land we are on. This includes my own roles and responsibilities as a settler. It also provided a useful theoretical map for thinking-through the complexities of participatory and counter-hegemonic work with young people and the role of imagining new forms, and ways of being (Tuck et al., 2008; Tuck & Yang, 2014b). Drawing on Wolfe's (1999) understanding of settler-colonialism as a structure, and not an event, I look to the ways in which scholars (Coulthard, 2014; Dhillon, 2017; Simpson, 2014; Veracini, 2010) tease

out material, narrative, psychic and structural dimensions of settler colonialism, so that I can trace their impacts and influences on narratives of engagement.

In contrast, Ahmed's (2000, 2014) work on the sociality of the encounter and 'will' also frames this work. By illustrating how our encounters (like engagement processes) are produced "between others, within particular or finite circumstances" (p. 144), her work allows me to unpack how engagement is a relational process. As Ahmed (2000) writes: "If we think of the encounters socially - that 'being' only emerges through and with others then we can think about how meetings between particular others do not necessarily presuppose a meeting between two already constituted beings" (144). Engagement, as I will further discuss, is like a meeting, where the will to participate often plays out.

Last, I am interested in critical feminist theory because of its focus on possibility. There is a rich history of feminist theorizing (largely led by women of colour) that de-constructs while also creating ruptures, and ripples (Sandoval, 2000). This work seeks to investigate the structural patterns of meaning, feelings, or consciousness that holds up many ideological underpinnings of engagement. Thus, I am particularly interested in the creative (i.e., generative) potential of engagement work, and its possibilities for creating new spaces of imagination. As Gaztambide-Fernández (2009) argues, "The structural challenge lies in rethinking how we relate to each other in space and how we become self-conscious about how the spaces we inhabit and the rules of those spaces delimit what we are able to imagine as possibilities" (p. 85). This was a fundamentally creative project – not only because I took up artistic forms in both data collection and in and through my own creative practice work, but because, like all dissertations, at the beginning I did not know what new knowledge we would collectively create.

Methods

My research design employs case study (Yin, 2003), and photovoice (Catalani & Minkler, 2010; Wang & Burris, 1997). I also draw on my own creative practice as a form of inquiry. My methods are described in-depth throughout the dissertation.

Case Study

Case study design is well-suited for exploring "how" questions about complex social phenomenon, and is particularly well-suited when boundaries between phenomenon are not clearly evident, and issues of context are particularly pertinent (Yin, 2003) – as is the case with engagement. Its focus on context is also compatible with my constructionist paradigm. My particular design involves multiple embedded case studies, where the units of analysis are 1): organizational sites and 2) individual stakeholder roles. In this particular study, multiple case study design is appropriate as each case serves a particular purpose. Additionally, each organization represents a very distinct engagement context within the larger HIV field: a sub-acute HIV hospital; a peer-led youth HIV prevention and harm reduction program; and an ASO.

There are also strong methodological rationales for case study design -- as connected to my theoretical framework. My theoretical orientations were identified in advance, as advocated by Yin (2003). Because I had different relationships with each organization, case study allowed me to focus on the *particularities* of my encounters within each site. This allowed me to reflexively reflect on how my relationships influenced what participants chose to share with me in different contexts, or how data collection workshops needed to be modified based on context. Last, the focus on the particularities of each case also fits well with my theoretical interests. Critical theory is deeply invested in the particularities of context, whether socio-political, economic, or historical. The focus on the particular encounter also cuts across feminist philosophical work that takes up

the production of difference. While sometimes I needed to generalize when looking across cases, I tried to do so in careful ways that resist easy generalizations, by being responsive to complex realities (Mohanty, 1995).

Photovoice

Photovoice (Gubrium & Harper, 2013; Wang & Burris, 1997) is a participatory visual research method that asks participants to use cameras to identify issues and possible solutions for change in their communities. Photovoice has been widely used and adapted within HIV research, with demonstrated success in documenting the lived experiences of people living with HIV, and in program and policy change (Mitchell, 2011; Schrader, Deering, Zahl, & Wallace, 2011; Teti, Murray, Johnson, & Binson, 2012). As an explicitly participatory method, photovoice is well suited to explore issues of engagement and participation, and connects well to our CBPR approach. For example, the method's open-ended structure (creation and discussion of participant-generated images) allowed participants to drive the research agenda, while multiple layers of information (photos, discussions, notes) helped me in understanding the nuances, strengths and particularities of engagement within and across organizational sites. Visual methods are also a generative site to prompt reflection, as I could ask participants what is in/outside/behind the photograph. Last, the methods are well-suited to my dissemination and social change goals. Images are very multi-modal (Pink, 2013), and when curated in a particular way, can provoke an affective response (Weber, 2008). Exhibitions can also play a pedagogical role in organizational change (Mitchell, De Lange, & Moletsane, 2017).

Photovoice is a highly facilitated process, as explored throughout. I was interested in crafting a process whereby participants could individually and collectively reflect on their lived

experiences in order to put forward collective understandings of engagement that could help organizations think more deeply, and in nuanced ways about what it means to involve community members in programming and policy efforts. In order to attend to the different needs of study participants, and the contexts of each organizational site, each set of data collection workshops was locally modified, with help from co-investigators affiliated with each of the sites. This type of adaptation is common, and in fact, advocated by other photovoice researchers (Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Flicker et al., 2017; Latz, 2017). These modifications are discussed throughout.

Creative Practice

I also used installation and poetry as a site to work through my own conceptualizations of engagement in the research. Traces of this work can be found throughout the dissertation. Using installation and poetry as a form of inquiry has a rich tradition in qualitative research (Cole & McIntyre, 2008; Davis Halifax, 2004; Leavy, 2009). Given the complexity of conducting collaborative work, it was important to have an independent site to reflect on my own conceptions of the work, and how this dissertation, and larger study touched me. This is in keeping with the principles of critical, feminist research as discussed above. While I don't propose that we can ever truly know ourselves, or can make fully transparent our ideological or political biases, working with poetry allows a different way into thinking through one's affective investments. As Herising (2005) argues, "The imperative for researchers […] is to take a critically active stance that takes into account (and accounts for) multiple histories and traces diverse trajectories that give shape to various meanings, authorities, power and ways of knowing" (Herising, 2005, p. 133). This was particularly important when grappling with the ethics of representation, and my desires not to "fix" communities through participatory visual processes (See: Switzer, 2018)

Last, working in and through my creative practice, also supported me in seeing the 'beyond' of this work as explored throughout. As Muñoz (1996) writes, "art conveys, translates, and engenders structures of feeling – tropes of emotion and lived experiences that are indeed material without necessarily being 'solid'" (p.10). This creates a queer process of continually relating to the "traces" or "glimmers" of lived experience within a work. Like Muñoz, I see the integration of my creative practice within this dissertation as a queer act – it disrupts normative ideas of evidence. Both poetry and installation refuse to 'fix' meaning or experience – what Salverson refers to as "meanings touched but not pinned down" (p.125). Thus "making work that becomes, like a perpetual horizon, rather than an artifact of experience; making work *that acts as if rather than says it is*" (Jones & Adams, 2010 emphasis mine).

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ethics of representation

your words in my hands,
weighted like stones
in my pockets, these
inked pauses, these
tracings

your words in my hands,
anxiety like a hockey puck
shallow breath in
the deep end

your words in my hands,
a tracing of a foot, oiled
on the wood floor
That's not what I said.
I knew them – those kids.

your words in my hands,
when you cannot speak for yourself
now passed from this world,
and onto another

your words in my hands
your words in my hands
your words in my hands

your words in my hands,
snip, snip, snip
who am I to punctuate
these ellipses, a speckled
litter, a tracing, a haunting

your words in my hands,
a doctor with a scalpel
is this where researchers,
get their god complex?

your words in my hands,
selection requires
exclusion. oh,
what a weight.

Chapter Two

Community Report: Picturing Participation: Exploring engagement in HIV service provision, programming and care.

One of the goals of the larger CBPR project was to create a series of resources to help organizations think more deeply about the complexities and nuances of engagement. The following chapter shares a community report co-authored as part of this project (Switzer et al., 2017). I led the development of the report writing process, including collaborative analysis, however this report would not be possible without the voices of many. This chapter provides supplementary information on the report, including information about co-authorship, workshop and collaborative code-book design, report writing, and its larger aims. Where possible, I have tried to reduce duplication, and provide information that is not discussed in the other chapters, or in the report itself.

The purpose of this particular report is to provide a brief overview of project findings in order to help organizations, and those who work within them to think more deeply about the nuances and complexities of engagement in the HIV sector. When asked to take photographs that represented their understandings of engagement, stakeholders' images and narratives reflected on the following seven themes: personal and organizational journey; honouring relationships (with self, other, and land); accessibility and support; advocacy, peer leadership, and social justice; grief, loss, and remembrance; and non-participation. These themes are explored throughout the report. Because engagement is such an abstract term, and is highly shaped by institutional context, each of these themes provides a site for organizations to reflect on the process of designing, or leading community-engaged programs and services in a way that moves 'engagement' from rhetoric to

practice.

The report does not serve an academic audience, nor is it an academic output. Some of my thinking has deepened since writing this report. If I was to write the community report today, it might look very different. This community report was designed to be used in a timely and accessible way by community members, and local stakeholders. In contrast to academic work that is produced over time, the report needed to be produced quickly and efficiently, in order to piggy-back on the momentum and energy of the CBPR project, and to support our public exhibit(s). What is 'lost' in theoretical sophistication, is gained in relevance, wide uptake, and accessibility. I will return to these contributions in my final chapter.

From the ground up: Writing the report

The report was co-authored by members of our research team, including research assistants, and community co-investigators. Participants, who consisted of 36 stakeholders at three unique organizations providing HIV prevention programming, HIV service provision, or clinical care, also played a key role. Sites represented different organizational contexts within the HIV sector, and served different communities. The details of the sites are described in the report, and other chapters. Participant demographics are also discussed in subsequent chapters.

The analytic and writing process followed three stages. First, analysis began with participants in our last photovoice workshop at each site. Second, I led the research team in a collaborative analysis process, which included organizational representatives – some of whom were also present at the photovoice workshops. Third, I took a leadership role in drafting the report, and obtaining feedback from a smaller working group of team members.

Phase 1: Photovoice Process

Over a period of six months, 20 audio-recorded workshops and 17 photo-elicited interviews

were conducted with participants. Workshops were designed by myself, with input from organizational representatives, who were also co-investigators. They were co-facilitated by myself, and a peer research assistant who was hired from one of the sites. Research assistants from York University also provided administrative and logistical support.

We used photovoice based on the work of Wang (1999), in order to explore people's ideas around engagement. Photovoice is a highly facilitated method, and can be adapted to different ends (Catalani & Minkler, 2010). The specific design of photovoice workshops varied by site[1], however, at each site we: introduced the project; brainstormed ideas about engagement; provided training on ethics and photography; and supplied photography equipment and instructions for taking photos. Participants were asked to take a photo, or a series of photos to capture their understandings of engagement. They received a handout, guiding principles (e.g., no pictures of people without verbal consent), and optional sub-prompts generated with help of the research team, including community representatives. At each site, we discussed, and celebrated a selection of photos taken as a group. In some cases, we used photo-elicited interviews (Harper, 2002) in order to accommodate participant's scheduling and accessibility needs. Photo-elicitation is a semi-structured interview method where participants respond to participant or produced or researcher-produced images. In our case, participants participated in all other group photovoice workshops, but discussed their photographs by interview. (This is elaborated on elsewhere).

Discussion of photos followed a modified version of the SHOWED method[2] based on the work of Wang (1999). This method invites participants to describe what they see in the photo,

[1] The overarching design was the same, however, there were some notable differences. In some cases, we modified icebreakers to meet participants' needs and interests. Some sites had extended time (and support) in taking photographs. At one site, we separated clients from staff – as discussed elsewhere in the dissertation.

[2] SHOWED stands for: What do you **see** here? What is **happening**? How does this relate to **our** lives? **Why** does this strength, or concern exist? What can **we** do about it? Our questions used, and built on Wang's method.

make connections to the topic (e.g., engagement), and their lives. This method also invites participants to make connections between photographs (their own, and others). This approach is inspired by Freirian (1973, 2000) principles of *conscientization* – a process of making connections between individual experiences, and larger structural issues. Here, we modified the traditional photovoice process as we were not only interested in issues, but ideas.

The workshops resulted in 67 participant-produced photographs and narratives for exhibition. In our last workshop, participants at each site looked across their photographs and narratives and identified common themes. I asked them to take a gallery walk around the room, and notice the similarities and differences between photos. Participants were divided into small groups. Each group received a package of the photos (and associated narratives), some sticky-notes and some markers. Groups were tasked by organizing the photos by theme, and reported back on their themes. These report-backs were audio-recorded. Sticky notes were catalogued by site. Photos of this process are reflected in figure 1.

Figure 1 – Looking Across Photos

Phase 2: Collaborative Code-Book Development

Following the workshops, a sub-set of the research team – including one community representative from each site reviewed the transcripts from the 'report backs', and the photographs

and narratives. We met twice with the aim of developing a coding framework that cut across all three sites. Our first meeting consisted of a conversation on commonalities and differences between transcripts. Following this meeting, I cross-listed the sticky-notes from the workshops, and based on the transcripts and team discussions, I drafted a preliminary coding framework for further discussion and refinement to share with the team. The final framework consisted of seven themes, and sub-themes, as well as a few extra process-oriented codes that the team decided it would be useful to 'track.'

The 67 photographs and participant-created narratives were coded by our research team at a day-long meeting in September 2017. Prior to the meeting, photographs were numbered. Data was entered into NVIVO, and I used our draft framework to subsequently 'code' the transcripts. While I continued this process after the meeting, this allowed me to pull some key quotes for context. We used the DEPICT method, as developed by Flicker and Nixon (2014), to guide our work.[3] The DEPICT method is an analytic approach designed to include multiple perspectives in the research process. We began the meeting with presentations from community co-investigators, and our peer research assistant. These individuals were present at all the workshops, and helped other team members (who were academics or staff members) familiarize themselves with the data collection process. This also centered our community co-investigators -- who had less experience working on academic projects -- as knowledge producers. They expertly answered many questions from those with more institutional power, and played a leadership role in the analysis process.

From there, we worked in small groups (made up of team members in different roles). Each group received a package of all 67 photographs, and a worksheet labelled for a particular theme.

[3] DEPICT stands for: **D**ynamic Reading, **E**ngaged codebook development, **P**articipatory coding, **I**nclusive reading and summarizing of categorizing, **C**ollaboratively analyse, **T**ranslate**.**

The worksheets contained material as provided in table 1.

Sample Questions on Worksheet
• Completed by: _____ • Code name (and sub-code): _____ • List the pictures by # that speak to this code (e.g., 12, 18, 47) • What do these photos and associated narratives (as a collection) help us see? • How are they similar or different across 3 sites? • [Quotes listed for context] • After reading the quotes, and viewing the photos, do you have any new insights? • Anything else?

Table 1 – Collaborative Analysis Questions

Phase 3: Report Writing and Publication

Information on these worksheets were collated, summarized, and refined, to form the seven 'spreads' highlighted in the community report. Report recommendations and questions for consideration were created in conversation with research assistants and select community co-investigators (who expressed interest). The report was reviewed by a smaller working group of our team, who provided feedback on multiple phases.

Some of this feedback was also visual. For example, I worked with a skilled graphic designer to co-develop icons for each of the themes [figure 2]. Some of these icons received immediate approval from the working group. Other icons, such as non-participation, needed revision and required deeper input from multiple team members. The process of refining our themes into icons was very useful in helping further refine the 'meaning' behind each of the themes, in a way that was accessible and drew on the skill-set of all team members. Last, the icons were useful in our dissemination efforts. For example, we used the icons at our community exhibit to visually identify images belonging to different themes, on our website to organize photos, and printed them onto swag for participants.

Figure 2: Icons by theme

Dissemination

The report was printed, launched, and initially shared at our community exhibit to over 100 attendees. As explored more in chapter six, it has been shared widely across the sector. The report provides organizations with a concrete tool to facilitate conversations about meaningfully including people with lived experience in program delivery. Each of the 'spreads' contains questions for consideration, based on key themes. Having frank and transparent discussions that are grounded in quotidian realities can alleviate some of the challenges associated with the 'fuzzy' nature of community engagement (Dempsey, 2010)

Each of the seven themes also re-focuses engagement away from individual conceptions, towards relational, multi-dimensional, and/or organizational understandings (Barello, Graffigna, & Vegni, 2012; Belle-Isle, 2016; Marshall, Dechman, Minichiello, Alcock, & Harris, 2015). While some of these themes may be uniquely specific to HIV community-based organizations (e.g., loss and grief), many of our themes are applicable to, and have been discussed in other areas such as: mental health (Horn, Rauscher, Ardiles, & Griffin, 2014), harm reduction (Switzer, Chan Carusone, Guta, & Strike, 2018), housing (Garcia, Minkler, Cardenas, Grills, & Porter, 2014), and

youth engagement (Reich et al., 2017; Schulman, 2006). For example, the importance of relationships, journeying together, and the bumpy road of navigating difference when working in a project unified by a singular identity (e.g., HIV), are transferrable to many other engagement contexts. A copy of the community report is provided herein.

When referencing the report, please cite it as:

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PICTURING PARTICIPATION

EXPLORING ENGAGEMENT IN HIV SERVICE PROVISION, PROGRAMMING AND CARE

York University / Université York
University of Windsor
EMPOWER
Parkdale Queen West Community Health Centre
Canadian Foundation for AIDS Research
Concordia University
University of Toronto Dalla Lana School of Public Health
REACH 2.0
PWA
30 Years 1987-2017
Casey House

"I love seeing the candle *not* lit, but there's times when I like to see the candle lit, because I know that person isn't suffering anymore" – CASEY HOUSE CLIENT

This report is dedicated to all those we have lost in this project, in our families, and in our communities.

PROJECT DESCRIPTION

PICTURING PARTICIPATION is a community-based participatory research project that uses photography and other creative mediums to reflect on the meanings of engagement in the HIV sector. We are a team of community members, researchers, and service providers that partnered with three local organizations to do this work.

The principles *Nothing About Us, Without Us* and the *Greater Involvement of People Living with HIV/AIDS* stress the importance of meaningful inclusion of those living with, and most impacted by, HIV in all aspects of the HIV response. We wanted to document how these principles were being understood and operationalized in diverse community settings: a youth-led HIV prevention and harm reduction program, an AIDS service organization, and a community-based HIV hospital.

Over a period of 10 months, we held 20 interactive workshops (and 17 interviews) with 36 clients, participants, peer workers, volunteers (with lived experience) and staff members at three organizations. We gave everyone a camera and asked them to take pictures that answered the question: *what does engagement mean to you?*

Together, we visually represented, discussed, and analyzed how we understood engagement, and what it looks like in practice at three different sites. Engagement was broadly defined – from participating in programs; to influencing decision-making (within an organization, a program, or in one's care); to co-leading programs or services.

We organized our key findings into seven themes identified here:

REFLECTING ON JOURNEY

HONOURING RELATIONSHIPS

ACCESSIBILITY AND SUPPORT

ADVOCACY, PEER LEADERSHIP & SOCIAL JUSTICE

DIVERSITY AND DIFFERENCE

GRIEF, LOSS AND REMEMBRANCE

NON-PARTICIPATION

This report has been designed to help communities think more deeply about how to support and foster diverse forms of engagement for HIV programs and community-based organizations. We share representative photographs and quotes to help illustrate themes and inspire conversation.

Names in report were chosen by participants; many are pseudonyms.

SITES

Casey House is Canada's first and only stand-alone hospital for people living with HIV/AIDS. Casey House opened its doors to clients in 1988 in a house on Huntley street. In the Spring of 2017, Casey House moved into a modern new facility and expanded its services. Casey House continues to provide a continuum of care to those living with HIV. It offers 14-sub acute care beds, a day health program, and community outreach for people living with HIV.

Empower – a program at Parkdale Queen West Community Health Centre (PQWCHC), is a youth-led HIV prevention, sexual health and harm reduction program that uses the arts to train diverse youth to develop and deliver educational workshops in their own communities. As a partnership between PQWCHC and Gendering Adolescent AIDS Prevention (New College, University of Toronto) Empower was in operation from 2010-2016, and complemented other agency programs such as harm reduction supply distribution, HCV programming for people who use drugs, and street and party outreach.

Toronto People With AIDS Foundation (PWA) is the largest direct support service provider for people living with HIV/AIDS in Canada serving men, transmen, transwomen and women living with HIV/AIDS in Toronto. Its mission is to engage people living with HIV/AIDS in enhancing their health and well-being through practical and therapeutic support services and broader social change, and to inspire them to live into their dreams and discoveries. Founded by people living with HIV, PWA has a long-standing history of engaging people living with HIV/AIDS in all facets of the organization, including its volunteer program which includes over 100 volunteers who give their time and expertise each week.

REFLECTING ON JOURNEY

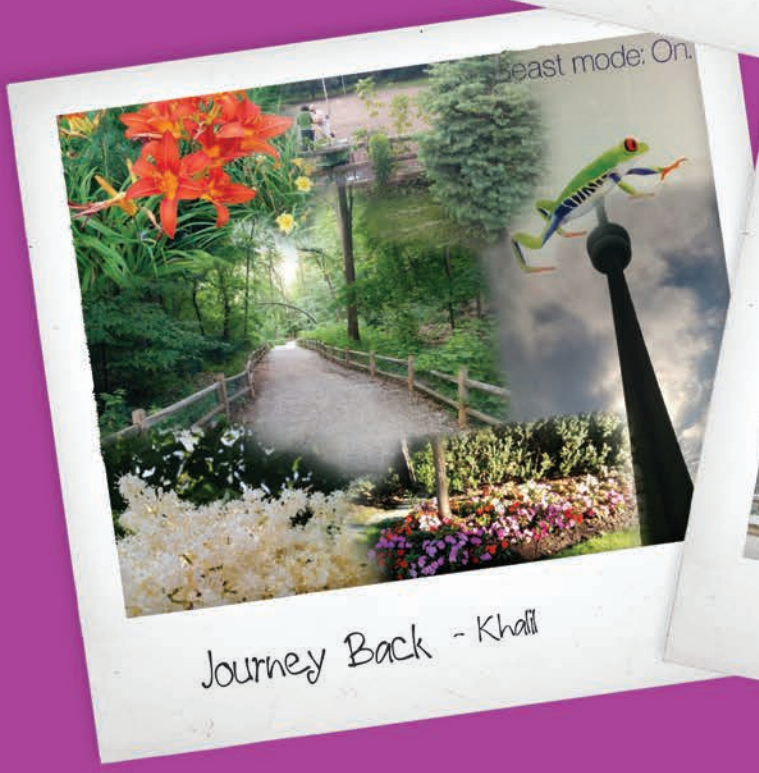
What's your story? How did you arrive here? Many participants depicted journeys, growth, and transitions in their photographs and narratives. In some cases, they were evoking literal migrations across continents, or across cities travelling to organizations. In others, they were referencing metaphorical roads towards healing, acceptance or personal growth. Participants also reflected on organizational change. For some, personal transformation was connected to, and intersected with, organizational change.

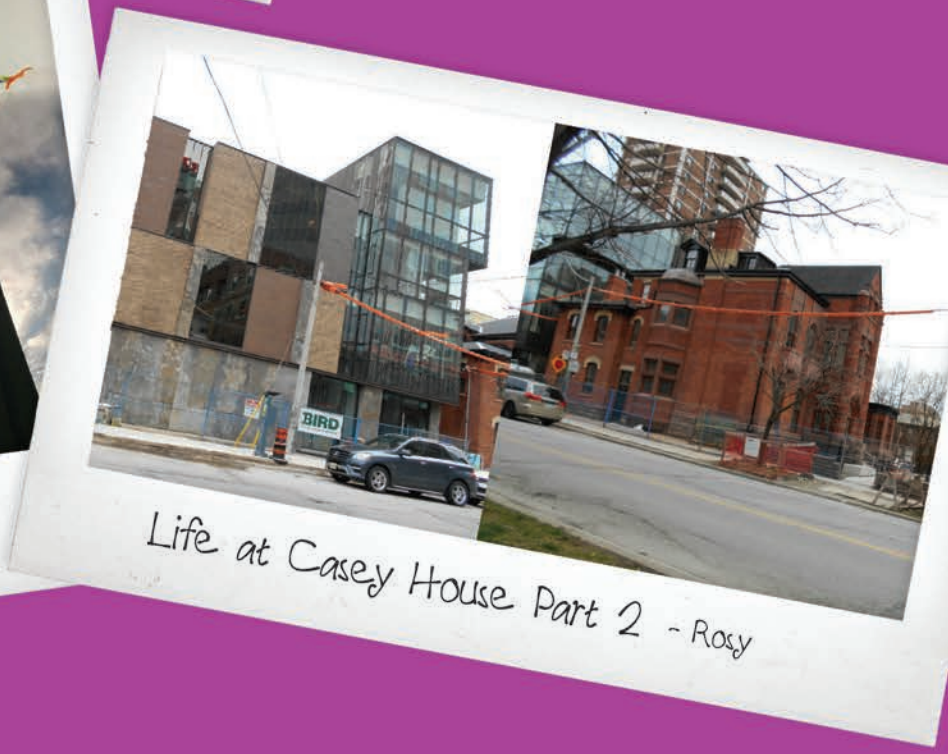
Although journey was important at all sites, what this looked like at each organization was very different. At Empower, participants captured images of plants and flowers in many stages (seeding, growing, blooming and decaying) to symbolize growth. They recounted how systemic barriers inhibited them from reaching their full potential, and spoke evocatively to the importance of inclusive spaces where they could bring their whole selves to the table. At PWA, participants photographed paths, and reflected on how PWA has helped them along in reaching their goals and dreams. At Casey House, participants referenced the construction of the new facility as a metaphor for re-building hope around health, and their desire to 'give back.' Transitioning from an AIDS hospice to a small community-based hospital, Casey House is now a place where people try to get well, be comfortable, or stabilize their health.

> "I chose, you know, to take a different path when I was diagnosed with HIV. … I am not going to let HIV [stop] me from fulfilling my dreams. … You can see it's here and it's up to us. You know, which way do we wanna walk?"
>
> **– PWA VOLUNTEER**

> "It's living, it's not dying. You walk through the door – it's open space again. It's a new beginning over there."
>
> **– CASEY HOUSE CLIENT**

> "I found my voice … I feel that's growth, finding your voice or reclaiming your voice. … I think that the more you give yourself permission to shine, the more you give others permission to do that as well."
>
> **– EMPOWER PARTICIPANT**





QUESTIONS TO CONSIDER:

1) In our project, peoples' motivations for engaging in programs or decision-making was often connected to personal or organizational journey. How might leveraging the metaphor of journey help your organization engage community members in decisions about organizations, in peer-led programs, or their care?

2) Many participants spoke about their organization's journey to intentionally become more inclusive to broader communities living with, and affected by, HIV. What's your organizational story? How do you share it? Do communities have the resources and power within your agency to intentionally shape it? How do the personal journeys of community members you serve influence the services and programs you provide?

For more photos and narratives (by theme), please visit:

https://pictureparticipation.wixsite.com/gallery

HONOURING RELATIONSHIPS

In our project, participants spoke about many different types of relationships (e.g., with oneself, with others, with HIV and Harm Reduction organizations, and with the land). Participants felt that their personal relationships with other volunteers, peer workers, participants, clients, or staff directly contributed to cultivating a sense of community and belonging at their respective agencies. These interpersonal connections laid the foundations for them to be able to work together collaboratively on larger projects, deliver peer-led services, or work on personal health goals.

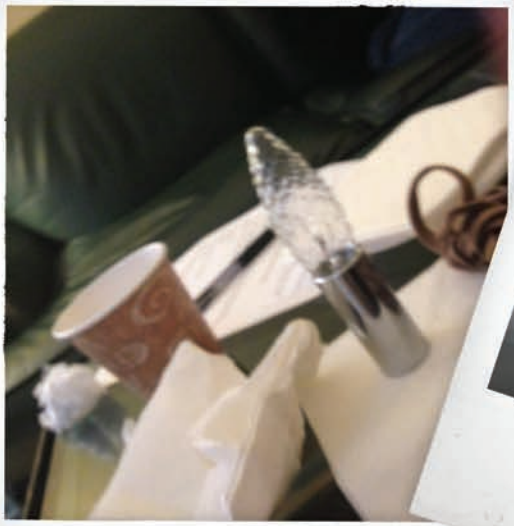
Many participants drew on visual metaphors of the environment as a site to reflect on relationships within organizational or communal ecosystems. For some, however, the connection to land was more material; in these instances, participants reflected on the history of this land, and our responsibilities as either settlers or members of Indigenous communities.

> "We can hit roadblocks and we can hit traffic jams…it's sort of communicating through those so that we aren't compromising what we've built and where we're going. But learning how to sort through that so that we can stay engaged with each other."
>
> **– CASEY HOUSE STAFF MEMBER**

> "No, I am not weird, I'm not wrong, it's not me, it's their discomfort. And to be able to go somewhere to that community that embraces you for who you are. I love that, and I feel like that's definitely what Empower did to me … It really unleashed me to be who I want and be happy with that."
>
> **– EMPOWER PARTICIPANT**

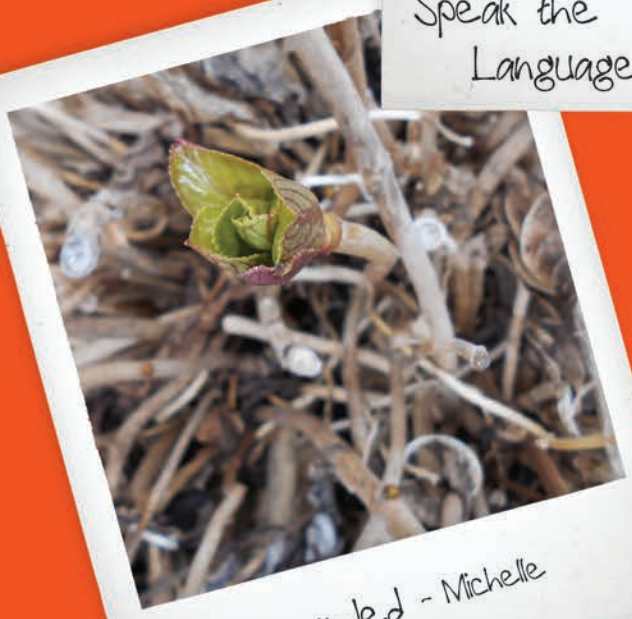
> "A lot of community clients here and residents, we're like, we just click. Some of us have been here for so long that you know it's like 'oh good we're in the house with you.' … There is one girl that I've known since I was 16 …and I am 35 this year. We met when we were young at other agencies when we first both became positive. And years later, we're back at Casey House."
>
> **– CASEY HOUSE CLIENT**

The Impressions We Leave Behind - Shona



Speak the Language - Robert

Untitled - Joanne



Surrounded - Michelle

Bee - Andrew

QUESTIONS TO CONSIDER:

1) Our participants continually taught us that it's the people who make the organization. How do you nurture and maintain relationships, when engaging people with lived experience in program and policy change?

2) What strategies does your organization or program have for centering different kinds of relationships (e.g., with oneself, with others, with other organizations, and with the land) in the work that you do?

3) Sometimes relationships and programs come to an end. Given that peer worker, volunteer and staff turnover is inevitable, how does your organization make sure that folks are supported through these transitions?

For more photos and narratives (by theme), please visit:

https://pictureparticipation.wixsite.com/gallery

ACCESSIBILITY AND SUPPORT

Experiences of people living with HIV and impacted by HIV are vast, complex, and wide-ranging. Identifying barriers to access and developing adequate supports for community members to meaningfully engage in decision-making or peer-led programming requires a close attention to organizational context, and the unique mental, physical, and emotional needs of community members.

Accessibility and support meant many different things to participants at each of our organizational sites. Under this umbrella, participants discussed:

- the ways they took care of each other as a community (i.e., informal support networks)
- organizational supports (i.e., trainings, events for volunteers)
- understandings of "safe" space
- opportunities for creativity as a form of support (i.e., art-making for different learning needs)
- access to agency services (i.e., medical, community programs, harm reduction)
- ideas of community-responsive programming (i.e., culturally-specific programs, spaces for youth 'aging out')
- barriers to engagement (i.e., fluctuating health levels, mental health, systemic issues)
- specific access needs (i.e., transit fare, food, pronouns, accessible/gender-neutral washrooms).

> "I see PWA as a tree with roots. And, the brightest is the diversity of people who access services here and also the volunteers that come here. PWA is a place where everybody when they come here, they feel it's a safe space to be for them. It's like a home for them."
>
> **– PWA PEER WORKER**

> "So, when I think of the barriers and limitations, I see holistically. For me the missing wheel can be that intersectional component. Sometimes we look at youth only... Look at one experience that could be happening, and not considering the many factors that influence our lives."
>
> **– EMPOWER MENTOR**

> "Some people can't go home and talk about how they're feeling because people don't know about their status. … So, I think being around people who are going through similar things [as] you are – that's important."
>
> **– CASEY HOUSE CLIENT**

> "Trust is important because you don't want to feel like you have to lie about stuff."
>
> **– EMPOWER PARTICIPANT**

QUESTIONS TO CONSIDER:

1) To access programs at your organization, what are community members' specific support and access needs? Consider physical, social and structural barriers.

2) What supports do community members need to *adequately* and *meaningfully* contribute to decision-making or peer leadership in your organization or program? How willing and flexible is your organization to share power associated with the planning and delivery of peer-led programs and services?

3) What strategies do you use to build trust within your organization? Do community members trust that you will take their feedback seriously? Do they feel "safe" enough to provide feedback on programs and policies, without fear that it will jeopardize their access to services or opportunities?

For more photos and narratives (by theme), please visit:

https://pictureparticipation.wixsite.com/gallery

PEER LEADERSHIP, ADVOCACY, AND SOCIAL JUSTICE

Principles like *Nothing About Us Without Us* and *GIPA (the Greater Involvement of People Living with HIV)* have been central to the HIV response since the early 80's. From influencing program and policy design, to leading programs and services, participants spoke to the importance of being meaningfully engaged in their respective organizations. For some participants, they also saw their participation in this project as a form of advocacy.

While participants at all organizations saw their lived experience as expertise, how participants saw their role in influencing social change was significantly impacted by the contexts of the organization and the possibilities therein. For example, participants in Empower, a youth-led HIV prevention and harm reduction peer education project, saw clear parallels between their identities and experiences, systemic injustice, and their work as youth leaders in the broader community. In contrast, participants at Casey House and PWA - service-oriented organizations - saw advocacy and peer leadership as something that happened more internally (i.e., how to improve services), and in some cases, around broader anti-stigma efforts outside of the agency.

> "[It] reminded me of community, the way we need to be connected to one another. We can mobilize in ways that we might not be able to on our own."
>
> **– EMPOWER COORDINATOR**

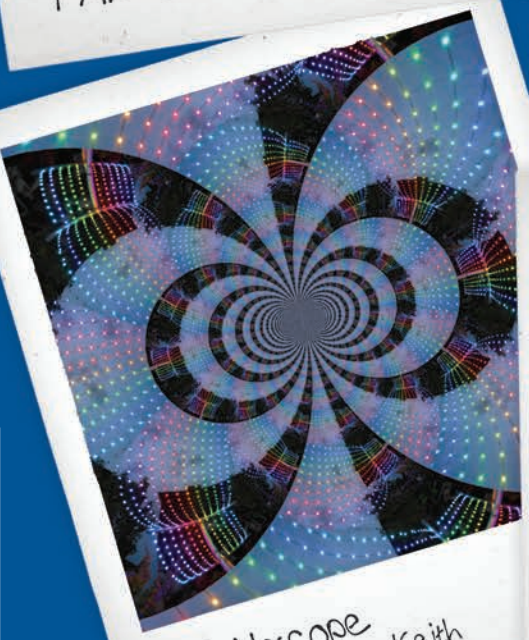
> "I took this photo as advocacy - to show my face, to make a difference."
>
> **–PWA PEER WORKER**

> "I mean I can volunteer at church or anything else like that, but this place is important to me. … Right now we want to be in charge in a group. … And it is important to keep myself busy and focused. … We need each other. … My thing is to always talk about peers helping peers."
>
> **– CASEY HOUSE CLIENT (ON THE IMPORTANCE OF PEER PROGRAMMING)**

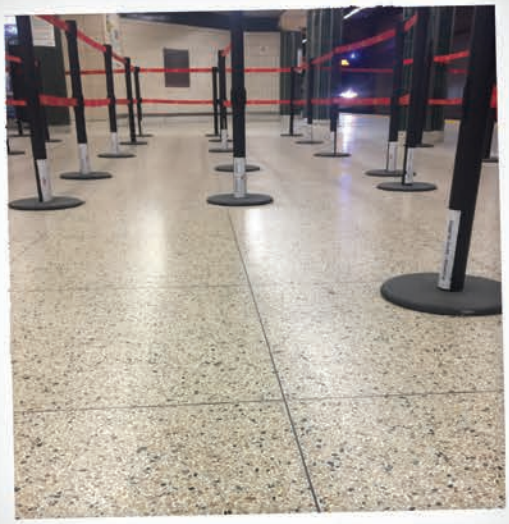
> "We've had different volunteers come here …. we're just the latest cohort of volunteers, I am sure people have heard in this agency, 'wait for us, they are just picking up the baton'."
>
> **– PWA PEER WORKER AND VOLUNTEER (ON THE HISTORY OF GIPA AND THE HIV MOVEMENT)**

I Am a Volunteer - Yvette

Weapons of hope - Chantal



Kaleidoscope - Keith



Untitled - Kamilah

OMG Stonewall - DKO

QUESTIONS TO CONSIDER:

1) How do you define a "peer"? Some participants rejected the idea of peer based only on a singular identity marker like HIV status or age, and encouraged us to think about other intersectional factors (e.g., race, sexual orientation, gender identity, drug use experience, mental and physical health, housing).

2) Participants had a wide range of reasons for wanting to be involved in leading programs and services. These reasons ranged from peer leadership as ways to: advocate; connect with others; give back and stay busy; gain skills/experience; and deliver community-responsive programs. What opportunities for peer leadership exist within your organization? Do they correspond with peoples' desires for being involved and co-leading programs or services, or consulting on decisions?

3) What opportunities for advocacy and social justice exist within your organization? Who is your organization accountable to? Funders, or the community you serve? If you are limited by funding restrictions, are there ways to partner with external groups or projects to create opportunities for people to mobilize on issues of importance?

For more photos and narratives (by theme), please visit:

https://pictureparticipation.wixsite.com/gallery

WORKING TOGETHER:
DIVERSITY AND DIFFERENCE

Honouring the differences that make up our communities is vitally important. In the sites we worked with (an ASO, a community-based HIV hospital, and a youth-led HIV prevention program), participants came from many different communities, and held intersecting identities associated with their gender, race, indigeneity, sexuality, ability, immigration experience, class, drug use experience, and health status. Participants spoke about what it meant to listen and learn from people who were not like them; to work across difference without erasing it; and to work in solidarity with each other and their communities.

> "There is a perception that PWA is a white gay men's organization and I really, really bristle at that because I've been in this movement for really long time. … It pisses me off because there were women of color in this organization when it was being founded. There were straight men … there were lesbians. … You know to disappear all these people from our movement…."
>
> **– PWA VOLUNTEER**

> "Like now we are going to have the Pride. … I am not gay, I am not a man, but I get involved. …So me being out there as a coloured woman, an African … And [I want] to remove that notion that .... these activities are only for the Black people... Say like during the Black History month, only the Black people are there -- No, we don't do that."
>
> **– PWA PEER WORKER AND VOLUNTEER**

> "So when I think of some of the feedback we get from our clients there's that young substance user … And there is the older 50 years old, HIV 'seen all my friends dying' and they struggle to figure out how to share this space. But there's actually an opportunity to figure out how to share this space and leverage one another's kind of wisdom that they bring to the table."
>
> **– CASEY HOUSE STAFF MEMBER**

> "Is it ambitious to imagine youth programming that is all-encompassing of everything that we are? I think so, because I think by virtue of being all the different ways we come into programming, I think we're already fragmented in many ways. I don't think that programming can necessarily solve that but, maybe can alleviate it."
>
> **– EMPOWER MENTOR**

QUESTIONS TO CONSIDER:

1) How is diversity reflected within your organizational structures? How are the communities you serve reflected in decision-making roles in your organization?

2) How do organizations create spaces where we can work across differences without erasing them? What programmatic spaces or activities have you intentionally created within your organization for allyship and solidarity?

3) To be culturally-relevant and responsive to community needs, HIV and Harm Reduction programs are often designed for specific communities. As our participants taught us, this can unintentionally serve to fragment people's identities. How does your organization continue to build community-tailored programs and services while also recognizing people's many intersecting identities?

For more photos and narratives (by theme), please visit:

https://pictureparticipation.wixsite.com/gallery

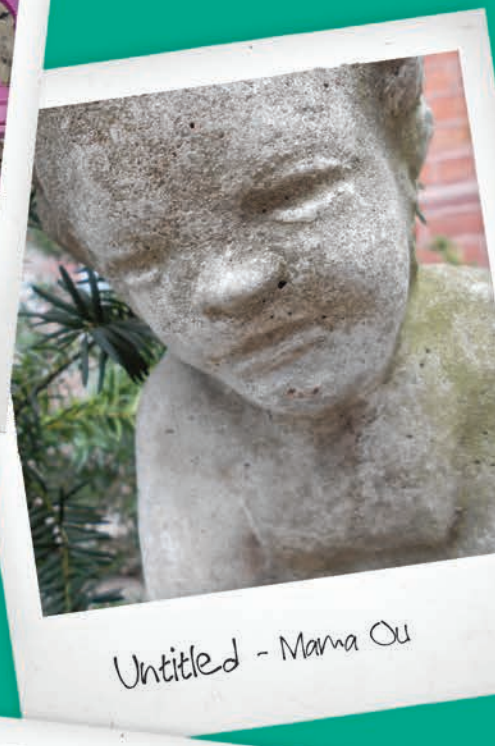
GRIEF, LOSS AND REMEMBRANCE

Loss and grief were dominant themes throughout the research. Many participants spoke about: experiences of losing loved ones; facing personal mortality; and loss on a societal scale through the AIDS or overdose epidemics. Participants also shared their feelings of grief, sadness and frustration as a result of dealing with ongoing systemic oppression, or programming spaces that didn't allow them to show up with all facets of their identity. Loss, however, was not always considered negative. Many participants spoke to the importance of hope and new beginnings in the face of loss.

> "I rushed all the burials, I rushed them and I thought I can escape by making my own film for them. I was in my own denial, not grieving. … I don't think I have grieved yet still for my cousin since she passed away. … It's the lifestyle of growing up in the hood…. What do I do? Like how do I control the situation? …. [This] could have been prevented by more cash, accessibility to drive to these communities to talk more suicide prevention, all of that."
>
> **– EMPOWER PARTICIPANT**

> "Knowing how. . . the epidemic has consciously changed somebody, how strong the impact may be on them, you know? … He said that, 'I see the rooms where my friends died'. He said, 'you know instead, I look across the street and I see life, I see hope and I see forward movement... memories and feelings associated with these walls'."
>
> **– CASEY HOUSE STAFF MEMBER**

> "Darkness is where you can regenerate first. And the first stage of grief, you have to go through to get to the second stage when you are marginalized or when you're first infected … It's OK to isolate a little bit."
>
> **– PWA VOLUNTEER**



QUESTIONS TO CONSIDER:

1) How has the HIV or overdose epidemic affected individuals (peer workers, participants/clients, staff, etc.) in your organization over time?

2) As our participants reminded us, loss sometimes creates rooms for (re-) generative possibilities. What strategies does your organization have for supporting community members and staff during times of loss?

3) Loss takes many forms. How might your organization consider larger systems of oppression (racism, transphobia, stigma against drug users, etc.) when thinking about loss?

For more photos and narratives (by theme), please visit:

https://pictureparticipation.wixsite.com/gallery

NON-PARTICIPATION:

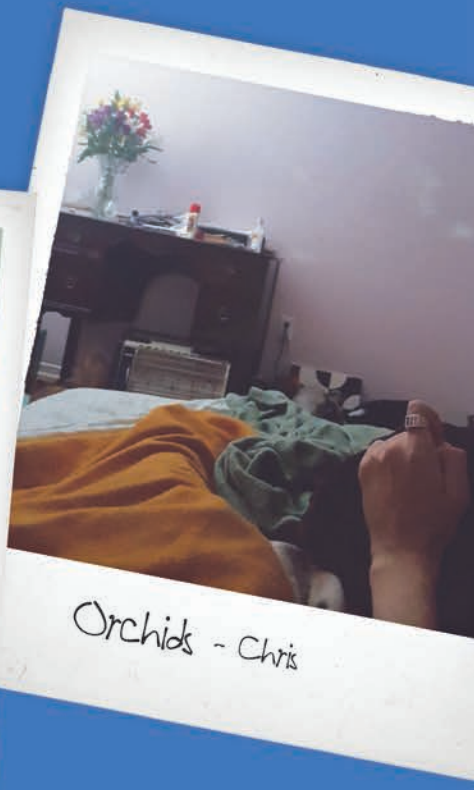
Sometimes people don't want to, or can't participate. Participants told us about: choosing to actively *not* participate as a form of self-determination; taking distance to heal or attend to one's physical or mental health needs; and the dangers of burn out. For many community members actively involved in peer leadership roles, they must carry multiple burdens, such as working with limited resources while also dealing with personal exhaustion and the weight of structural barriers. For others, just getting up and out the door when dealing with physical and mental health can be a large struggle.

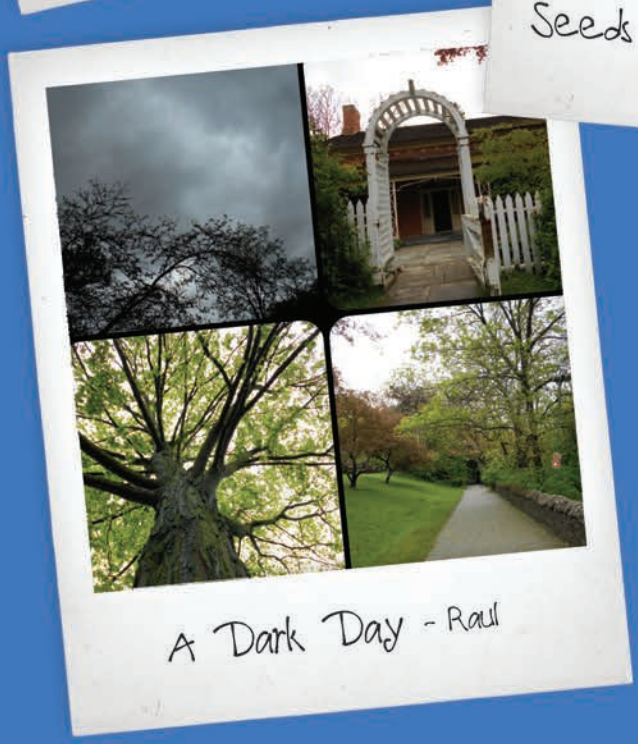
> "In terms of my own position as a trans woman, and also a woman of colour, there are so many rich stories, rich narratives that aren't told …. Sometimes I feel burnt out because I feel like a lot of pressure is on me, to deal with issues that have existed longer than I have."
>
> – **EMPOWER PARTICIPANT**

> "Just you know [the bench] was kind of away from the building, away from the nurses wherever anybody who was just trying to help. At that time, you are like 'ha, I just wanna get away'."
>
> – **CASEY HOUSE CLIENT**

> "Sometimes people need to be left alone to really determine things for themselves and develop an understanding of what their needs are before being around other folks, so like that's a way of supporting a person, by giving them some space. Fall back."
>
> – **EMPOWER MENTOR**

> "We rely on you, but do we not rely on you individually."
>
> – **PWA VOLUNTEER** (ON THE IMPORTANCE OF TAKING BREAKS OR TIME AWAY)





QUESTIONS TO CONSIDER:

1) Community engagement models often focus on levels of active participation. How might your organization reframe the ways it looks at non-participation? Are there ways to create more fluid entry and exit points for meaningful participation to accommodate people's interests, and/or mental and physical health needs?

2) For many communities, self-care must go beyond having a hot bath or cup of tea. Given the weight of structural barriers and systemic oppression, how do organizations better support peer workers and volunteers who may experience symptoms of burn out?

3) How might the idea of non-participation help us center principles of autonomy and self-determination in peer-led programs? Or lead to more sustainable, equitable, and accessible programs or services?

For more photos and narratives (by theme), please visit:

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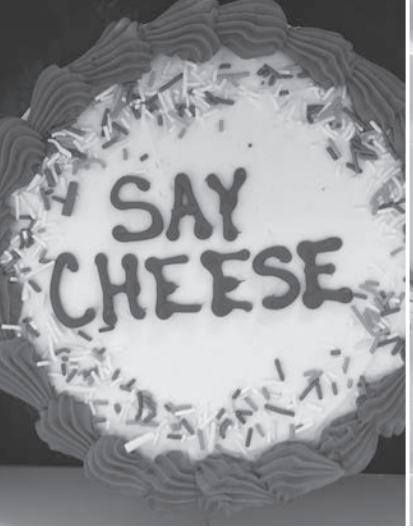
"By dreaming every day, dreaming with our hands, dreaming with our minds . . . Things are just starting."

– PWA VOLUNTEER

We believe that the HIV and Harm Reduction movement cannot exist without the insight, passion, and care of people living with and affected by these issues at the forefront. Whether your organization involves young people affected by HIV in larger prevention efforts, or people who use drugs in specific support services at AIDS Service Organizations, engaging community members must be done in ways that are **meaningful, sustainable** and **feasible**. We must not only dream it, but we must also do it.

RECOMMENDATIONS

1. Engagement has many different definitions. Organizational contexts and people's roles within them will shape how people understand engagement. Work with community members to define what engagement means at your organization, or within your program.
2. Consider the role of personal and organizational journey when designing peer-led programs, and spaces for individuals to consult on organizational change.
3. Honour relationships to self, to others, to your organization, and to the land. These relationships will form the backbone of your work together.
4. Ask community members what accessibility supports they need in order to be able to meaningfully consult on decisions and programs in your organization. In addition to tangible supports (transportation fare, connections to services, food, etc.), this may include support mechanisms to create inclusive programs across gender, race, sexuality, age, class, Indigeneity, drug use experience, and health status.
5. We arrive at organizations with different identities and experiences. These experiences are often linked to the privileges and oppressions we encounter in the world. Consider what it means to work across these differences in your work together.
6. Sometimes, participation can feel tokenistic. Create transparent and accountable dialogue and procedures around how peoples' input, decisions, and labour are being taken up and respected in your organization or program.
7. Reflect on the designation 'peer.' What does this mean within your organization? Consider who this label includes and excludes.
8. Create spaces for dialogue about the impact of loss and grief on community members and staff in your agency.
9. Consider whose voices are not at the table. Reflect on why this might be and where necessary, take action to address it.
10. Respect the importance of lived experience – in program and policy design; in peer-led initiatives and services; and in decisions affecting personal care. This may mean challenging deeply engrained organizational values.
11. Take careful note when people are not participating. This may provide valuable insight about how you consult people on important decisions, design inclusive peer-led programs or service delivery, and attend structurally to burn out.
12. Opening up decision-making processes to communities most affected by issues may change organizational plans, priorities or outcomes. Trust in this process – your organization or program will benefit in the long-run.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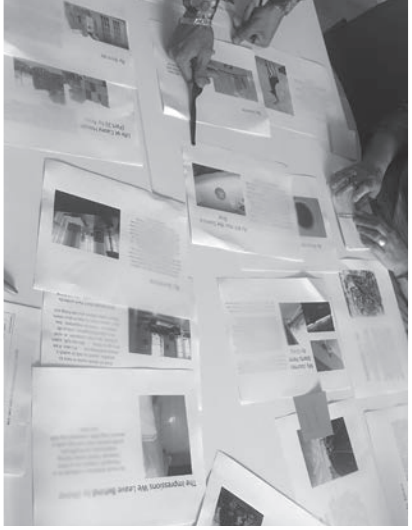
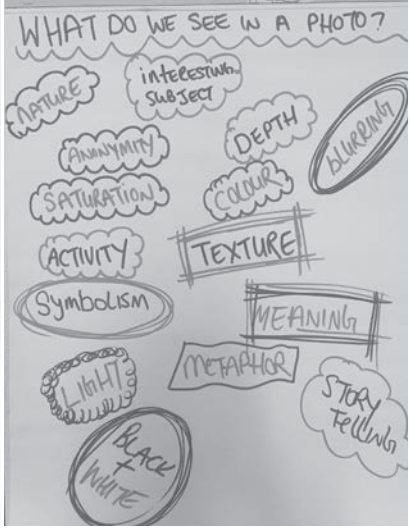
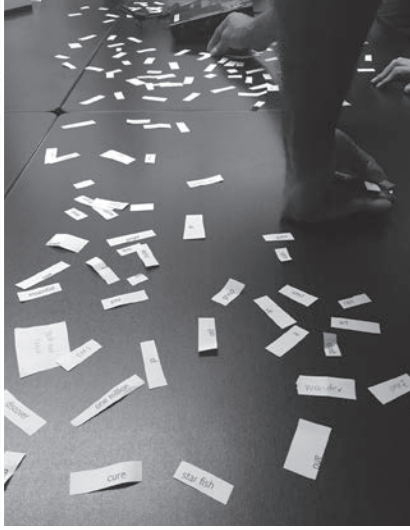
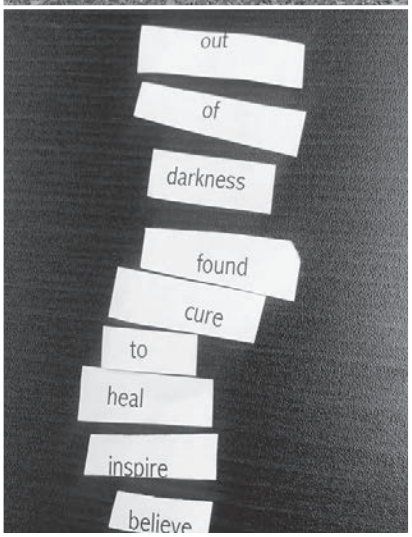



WHAT DO WE SEE IN A PHOTO?
NATURE
INTERESTING SUBJECT
DEPTH
BLURRING
ANONYMITY
SATURATION
COLOUR
ACTIVITY
TEXTURE
Symbolism
MEANING
METAPHOR
LIGHT
STORY TELLING
BLACK + WHITE




out
of
darkness
found
cure
to
heal
inspire
believe


Client/volunteer engagement
Services offered
outreach
human CONNECTION
PEER SUPPORT
Sustainability
VOLUNTEER
APPRECIATION
RELIABILITY
HOPE
SAFE SPACE
TEAMWORK
DIVERSITY
family
OPENING DOORS
NOT ALONE

ACKNOWLEDGEMENTS

Our workshops took place in Toronto (from the Mohawk word Tkaronto). This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, this meeting place is still home to many Indigenous people from across Turtle Island, and we are grateful to have an opportunity to build relationships on, and with this land – including with many individuals in our project.

A warm thank you to all the participants who: contributed to our project, and helped us learn and grow; and to all the co-investigators, and research assistants who supported the project. A special thank you to community report working group members, and staff at the three sites who provided such a warm welcome.

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Concordia University · University of Toronto Dalla Lana School of Public Health · REACH 2.0 · Pwa 30 Years 1987-2017 · Casey House

arrival stories

how is it that we arrive here?
orient ourselves in body,
space, and time,
this frontal lobe of a
meeting room, hospital,
health centre.

this place where relationships
are made, unmade, re-made.

this place where bodies
remember

what is it that
we do not know
and will always fail to grasp,
yet hold on to all the same:
your palm outreached
into mine, into each other's.

Chapter Three[1]

Journeying Together: A visual exploration of "engagement" as a journey in HIV programming and service delivery

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7 University of Windsor, Windsor, Ontario, Canada
8 University of Toronto, Toronto, Ontario, Canada
9 Centre for Addiction and Mental Health, Toronto, Ontario, Canada

Introduction

The *Greater Involvement of People living with HIV/AIDS* (GIPA) (Joint United Nations Programme on HIV/AIDS, 1999; Morolake, Stephens, & Welbourn, 2009); the *Meaningful Engagement of People Living with HIV/AIDS* (MEPA); and *Nothing About Us Without Us* (Jürgens, 2005) are widely cited principles within the HIV sector. Since the 1980's, HIV activists - in the context of enormous stigma and mass death – have mobilized for action from public health authorities, governments, and scientists (Gossett, 2014; Guta, Murray, & McClelland, 2011). This action paved the way for the development of HIV community-based programs and care supports, and engrained the principles of community engagement into the HIV sector from the beginning of the epidemic (Epstein, 1995).

Within the HIV sector, scholarship on engagement has been primarily conducted on the impacts, facilitators, or barriers of implementing GIPA/MEPA in organizational contexts – in

[1] This manuscript will be submitted to a health journal.

particular, AIDS Service Organizations (ASOs) (Collins et al., 2007), or in community-based participatory research (Travers et al., 2008). Some research has focused on the health impacts of engagement on individuals themselves (Genberg et al., 2016). Organizationally, the integration of GIPA/MEPA can produce: more relevant and responsive services; improved access to healthcare for people living with HIV; increased capacity-building; and decreased stigma within organizations. Implementing GIPA/MEPA, however, can create challenges related to: tokenism; disclosure and confidentiality; burn-out; changing boundaries and power dynamics; social exclusion *within* HIV movements (i.e., lateral violence); clarity around the term 'peer'; and the increasing professionalization and bureaucratization of some HIV community-based organizations (Carter et al., 2015; Li et al., 2015; Travers et al., 2008).

The experiences of people living with, or impacted by HIV who participate in research and programming are relatively-well documented. Yet, how people understand participation or engagement, or how it functions discursively, is undertheorized (McClelland, Guta, & Greenspan, 2018). Participatory processes are not neutral (Chiu, 2008; Cornwall, 2008), and how groups travel, or 'journey together', is as important as the 'end' (if there even is one). For example, tokenistic attempts at inclusion, or engagement processes that are not tailored to specific circumstances, needs or desires of communities, can at best, do nothing, and at worst, create harm to those involved – especially for communities who experience heightened forms of marginalization, such as communities of colour, Indigenous communities, and/or people who use drugs (Damon et al., 2017; Dhillon, 2017; Kwon, 2013). Scholars have also noted how the discourse of GIPA/MEPA may conceal larger structural inequities, and emphasize individual, rather than state responses, to the epidemic (Guta, Flicker, & Roche, 2013; McClelland et al., 2018).

Furthermore, given the ubiquity of terms like participation and engagement, there is a growing interest to define these terms (Chiu, 2008; Cornwall, 2008). Here, we define 'participation' as the *concrete* activities of involvement, or as the etymology suggests, to 'take part.' 'Engagement' includes this set of participatory practices (and hence participation), as well as people's *subjective* understandings of what it means to actively participate in, or (co)-lead programs or services. These understandings are often impacted by larger field or disciplinary discourses, as well as larger structures of power (Cornwall, 2008; Dhillon, 2017; McClelland et al., 2018). Engagement processes are often invited, facilitated, and employed within state-funded institutions (i.e., community-based organizations, hospitals, universities).

In our study, we set our conceptual efforts on exploring engagement within the context of community-based organizations providing HIV programming and service delivery. We asked stakeholders at three HIV community-based organizations to photograph their contextual understandings of engagement. Participants chose to tell us about their individual or organizational journeys, thus suggesting that journey may be a ripe site for discussing engagement. A journey implies a long, sometimes challenging and arduous, trek. It evokes notions of change over time, deep learning through praxis, and attention to process.

In this article, we employ a visual and thematic analysis of our findings, by focusing on participants' use of journey metaphors to discuss 'engagement' within and across sites. We demonstrate that understandings of engagement are shaped by organizational context(s), and participants' respective role within them. Taken together, visual metaphors of journey provided participants with a site to make sense of their experience, emphasizing that for many, engagement was a dynamic and relational process, rather than a fixed end, or instrumental means. Looking at engagement through the lens of journey may move our conversations beyond facilitators and

barriers towards how we might do this work together, and the role(s) of organization(s) in enabling this process. We conclude with a series of questions that may support organizations in thinking about engagement through the lens of journey within their respective organizations.

Methods

Collaborative Study Design

Following a community-based participatory research approach (Wallerstein, Duran, Oetzel, & Minkler, 2017) and case study design (Yin, 2003), a team of academic researchers, community members and service providers from three Toronto-based community-based organizations partnered to design and implement this study. The three organizations, People with AIDS Foundation (PWA), Empower, and Casey House are described in table 1. The lead author (Switzer) had prior experience working with each site.

Site	***Toronto People with AIDS Foundation (PWA)***	***Empower Program***	***Casey House***
Description	Canada's largest direct support service provider for people living with HIV/AIDS; programs and services are led, and supported by over 100 active volunteers living with HIV.	a youth-led HIV prevention and harm reduction program that uses the arts to train diverse youth to develop and deliver educational workshops in their own communities. Youth are mostly impacted by, but in some cases, living with HIV.	Canada's first and only stand-alone hospital for people living with HIV/AIDS. It offers in-patient sub-acute care, a day health program, and community outreach for people living with HIV.
Number of participants	10	11	15
Stakeholder Roles	5 volunteers; 4 peer workers/volunteers; 1 coordinator	5 program participants; 1 coordinator; 5 peer mentors;	9 clients; 6 staff (i.e., clinicians, coordinators, administration, management)
Involvement in program	1.5-10 years	1-5 years	<1-26 years
Age range in years	35-53	22-29	35-55

Table 1 – Site Descriptions

We used photovoice (Wang, 1999), a method where participants are given cameras to identify, analyze and discuss issues or ideas in their communities, to explore what engagement

meant to participants themselves. Taking and discussing photographs can create distance from one's everyday life by encouraging individuals to reflexively 'see' issues from new perspectives, and help make abstract ideas concrete (Mannay, 2010; Switzer, Guta, de Prinse, Chan Carusone, & Strike, 2015). Based on ideas of Freirian (1973) dialogue, photovoice involves participants as active subjects and knowledge co-producers in research (Gubrium & Harper, 2013), making it a good fit for our collaborative study. Our research design is captured by figure 1.

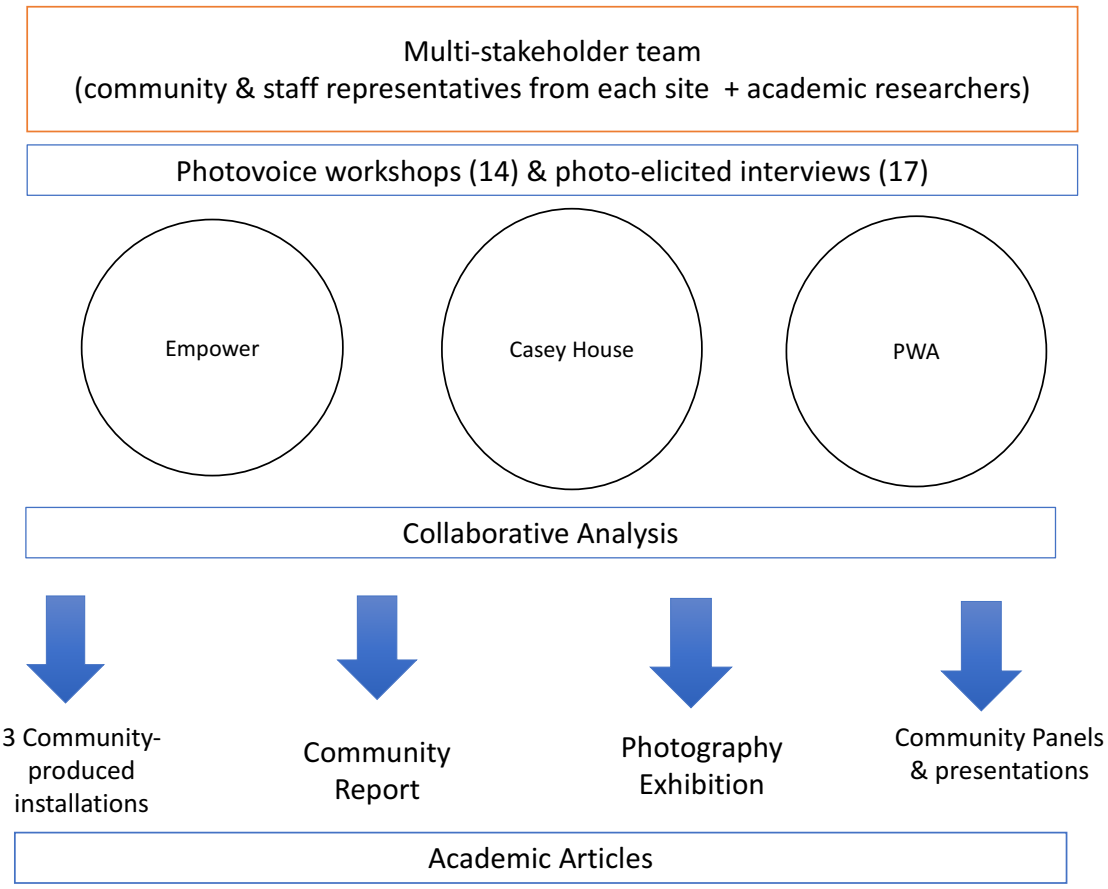

Figure 1 – Overall Project Design

Sites were chosen to explore a diversity of organizational contexts within the HIV sector (see table 1). Each organization works with a different population, has unique program mandates and governance structures, and has unique structural and funding challenges. Empower - a youth-

led HIV prevention and harm reduction program – is led entirely by young people. Until 2016, the program operated on precarious, youth-led grants, and had autonomy within a community health centre that had a long history of peer-led programs and services. PWA is an ASO run by people living with HIV and their allies. The organization has an active volunteer program where people living with HIV take on professionalized volunteer roles. Casey House is a clinical site designed to serve people living with HIV with complex physical, mental, and cognitive health issues. Hospitals tend to be more hierarchical than other sites, and operate with clearly defined staff and client roles.

Study Population and Eligibility

The study population (n = 36) consisted of diverse stakeholders in variety of different roles at each site. There are many complexities and nuances of designing peer-led programs within HIV community-based organizations, and often stakeholders will have different perspectives (Broeckaert, 2018). Eligibility criteria varied by site. At Empower, we recruited former program participants (peer educators), mentors (youth hired to support and train participants), and a program coordinator (also a youth – defined as 29 or under). Empower was without program funding at the time of the study. At Casey House, participants were either clients (60%) or staff (40%). We used targeted recruitment to capture diverse staff roles. At PWA, we recruited former or current volunteers (although only current volunteers participated), as well one coordinator. Here, some volunteers also held peer worker roles. Except for at Casey House, participants often held different roles over time.

Our final sample was extremely diverse in terms of age, race, gender, indigeneity, sexuality, HIV status, health, role and experience. Participants were asked to complete a short, open-ended, demographic survey. The PWA sample was comprised of a mix of white, and

racialized gay or bi men and heterosexual, African, Black women. Many participants were born outside of Canada, and reported being in good health. The Empower sample was younger, and predominately identified as 2SLGTBQ+. Slightly over half of the youth were Black, Indigenous or people of colour. This site was the most diverse in terms of gender identification (almost half did not identify with binary classifications of gender). Many Empower participants identified struggles with mental health and/or having an invisible disability. The Casey House sample differed by client or staff role. Here, participants were relatively divided along gender (cis male/female), however staff were more likely to identify as female. More than a third of Casey House clients were racialized, including those who were Indigenous; most staff were white. Slightly over half of all participants identified as heterosexual. Casey House clients have complex health care needs, and may struggle with physical, mental and cognitive health. Across all sites, drug use experience was mixed, however, active use was highest at this site.

Photographing Engagement: Workshop Design

Over a period of six months, we facilitated 14 photovoice workshops and 17 photo-elicited interviews. The format of the workshops differed slightly at each site to accommodate ethical and logistical issues, participant needs and interests. However, at each site we: introduced the project; brainstormed ideas together; provided training on ethics and photography; supplied photography equipment and instructions for taking photos; discussed, analyzed, and celebrated the photos taken. Following the photovoice workshops, we created site-specific photo-sculpture installations with participants using the photos. Based on participant feedback and previous experience (Switzer et al., 2015), at Casey House, staff and clients participated in separate workshops, discussed their photos by photo-elicited interview (Harper, 2002), and then came together in the final workshop. Discussions from workshops and interviews were audio-recorded and transcribed verbatim.

At each site, we asked participants to take photographs to explore what engagement meant to them. We encouraged participants to use photography as a mode of inquiry and creative expression. Participants received instructions and a list of tailored prompts developed with support from the research team, including community representatives at each site. Because engagement is an abstract concept, some participants needed assistance in concretizing the topic, prior to taking photos. In the instructions, we defined engagement broadly: from participating in programs; to influencing or participating in decision-making; to co-leading programs or services. This handout was reviewed by members of the research team, including community representatives, prior to being distributed. Before providing instructions, we led participants in a series of creative activities to center their initial ideas on engagement, and brainstormed collective understandings of engagement on a flip chart. We shared that we were open to multiple understandings.

Our workshops culminated in a curated exhibit of 67 photographs and narratives that was mounted in several community settings, three installations, a website, and a community report (Switzer et al., 2017). Our methodology has been elaborated on elsewhere.

Collaborative and Researcher-Led Analysis

According to systematic reviews, photovoice researchers seldom account for how participants are involved in the selection of images for analysis, exhibition, or for inclusion in published manuscripts (Evans-Agnew & Rosemberg, 2016; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). As part of the photovoice process, we asked participants to select photos for presentation and discussion at each of their sites. From these, they selected 1-2 photos for exhibition and generated accompanying written narratives. Then, at each site participants looked across their collective photographs and identified common themes. A sub-set of the research team

– including one community representative from each site – met to review this material and refine participant-generated themes into a master-framework that highlighted seven dominant themes: journey; honouring relationships; accessibility and support; peer leadership, advocacy, and social justice; grief and loss; working across difference; and non-participation.

Photographs and participant-written narratives were analyzed by our multi-stakeholder research team using the DEPICT method (Flicker & Nixon, 2014), with support from interview and focus group data. The DEPICT method is an approach to analysis that improves rigour by involving multiple stakeholders with diverse perspectives and experiences in the analysis process. Together, we collaboratively coded 63 images and associated narratives by theme and discussed the meanings of the theme as exemplified by the photographs. Discussions were recorded on worksheets, which contained supplementary information such as key quotes from the workshops.

Finally, the lead author (who was nesting her PhD dissertation within this study) supplemented this work with further in-depth analyses of 23 images coded for journey, associated narratives and supplementary transcripts. Here, photographs and participants' interpretations of the visual were complemented by the expertise of the lead author to identify patterns, connect findings to theory, and look across the data set (Drew & Guillemin, 2014). Images and narratives were inputted into NVIVO to explore the quantitative salience of themes based on exhibited photos. This practice draws on the work of Rose (2015), who suggests that looking at the visual quantitatively (when working with a large visual data-set) can produce new insights for qualitative studies. Finally, the team met to review this paper, provide feedback, and consult on implications for practice. Herein, the 'we' of this paper refers to the team of co-authors.

Findings

Participants understood engagement according to seven dimensions, as identified above. Figure 2 shows the salience of these themes, based on the 63 exhibited photos, as well as the percentage of photos coded thematically at each site. Here, the denominator is the total number of exhibited photos *per site*. Photos were coded for multiple themes. Our aim is not to reduce qualitative data to numbers, but rather, to show how certain themes aligned more strongly with particular sites, pointing to larger issues and trends. We reference these alignments throughout.

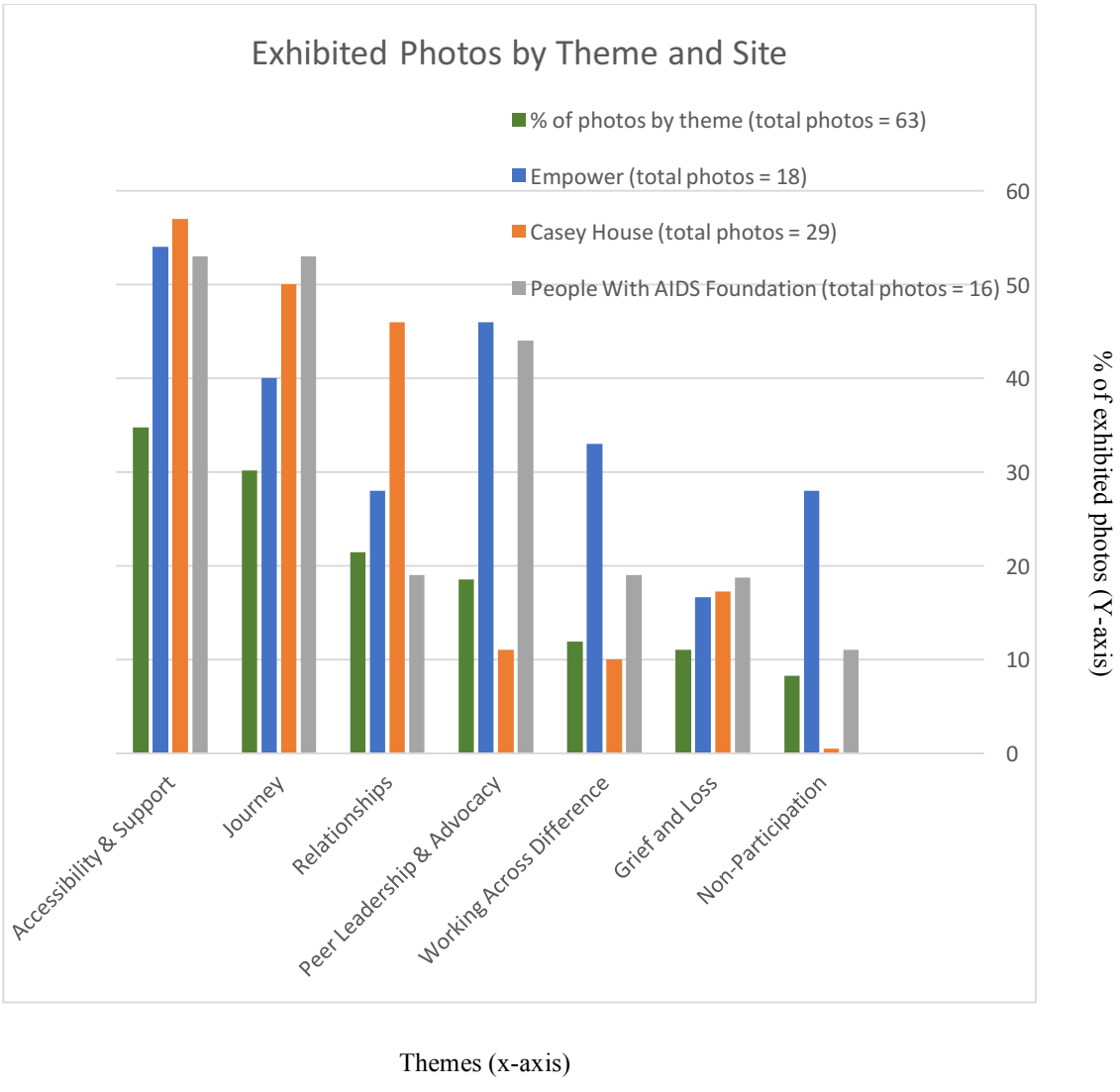

Figure 2 –Salience of themes in exhibit photos

Individual and organizational journey was a dominant theme at all sites. While slightly more photos were organized into the theme of accessibility and support, these issues are relatively well acknowledged within the literature (i.e, facilitators and barriers to involvement). Journey, however, provides a new, and generative site for thinking about engagement as a process shaped by organizational contexts, especially when explored by site. It is telling that when asked to visualize their understandings of engagement, many participants – across all sites – chose to take photographs that explored personal or organizational journeys. However, *how* journey was discussed and represented by site varied significantly, as illustrated by the unique metaphors participants employed in their photographs. Participants independently photographed paths (PWA), plants and flowers in different stages of growth or decay (Empower), or physical structures (buildings or parts of buildings) (Casey House) (figure 3).

In our study, participants told us how they wanted to be named when discussing their photos. Many of these are pseudonyms.

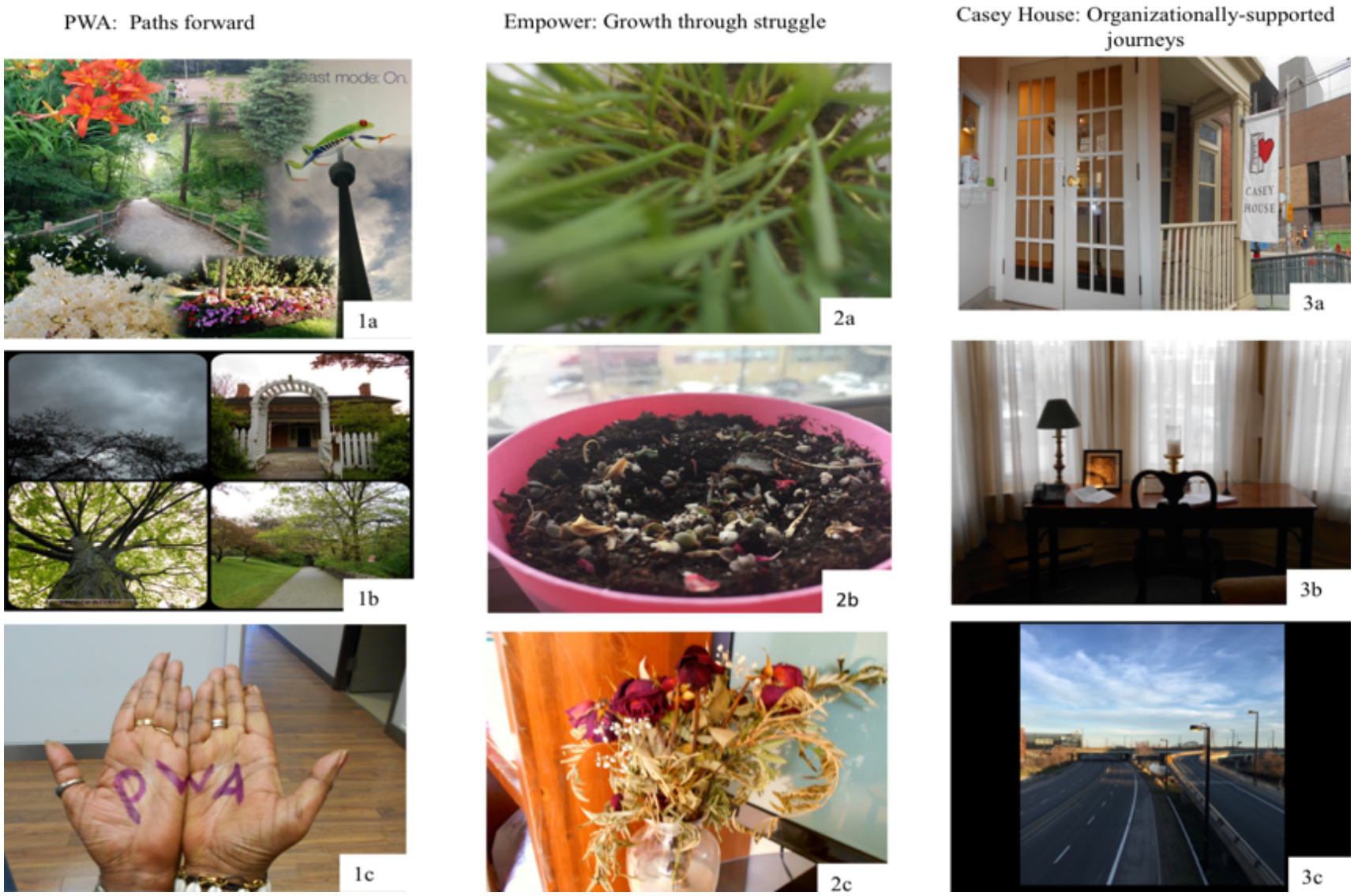

Figure 3 – Metaphors in journey photos [*From top to bottom, left to right: Journey Back - Khaleil; A dark day - Raul; Weapons of Hope - Chantal; Growth - Lydia; Seeds of our Labour – Buttercup; Emerging – Two Bite Brownie; Untitled – Brenda; Untitled – Robert; Open Road, Open Dialogue – Andra]*

"Life is a path: you decide which way to go": Journeying forward

At PWA, over half of their sixteen exhibited photos represented journey; of these photos, six visually depicted a path (see figure 3 - photo 1a, 1b). Participants spoke about their personal journey of HIV disclosure and acceptance, and the organization's role in supporting them through this process. For example, as Khaleil expresses in his narrative (photo 1a), "my involvement with PWA has taken me from isolation to a welcoming space of acceptance, services, hope, friendship and a new lease on life." Similarly, Raul collages four frames together (photo 1b), including two images of paths. In his narrative, he remarks: "In a dark day of life I seek for help, and found many possibilities that show me many ways, and above all, I could walk freely in a path because life continues even if it is a dark day." On another photo, the phrase "service access" (the name of a volunteer-run program) is collaged onto a tree, suggesting a connection between Raul's journey, agency services, and his role as a program volunteer.

Peer volunteers and workers are involved in all aspects of PWA from outreach, to service delivery and governance. PWA provides psycho-educational trainings for volunteers on how to leverage their experiences to become more effective peer allies. Many participants proudly referred to this role as a "supporter-to-supporter." As Khaleil articulated when discussing his photo, "I explain my journey and relate my journey to them [clients] […] I use that to help me and help other people. [….] to give other people hope." Many connected their healing journeys to their role in supporting others. As Keith wrote in his narrative (photo not pictured): "volunteer engagement is about fighting stigma and helping newly diagnosed find a clear path to resources, information and connecting people to supports with the community."

Participants also verbally and/or visually referenced light, darkness, and hope as connected to journey. These tropes were so instrumental to participants' understanding of engagement as

journey, that they influenced participants' final installation of a tree with photographs printed onto leaves using sunlight (See: *New Directions for Photovoice*). Participants spoke to the role PWA played in helping them cope with grief and loss during the "dark days" (figure 3- photo 1b) of their journey. Some participants also expressed how past struggles informed their decision to become advocates, volunteers or activists. Participants at this site frequently referenced principles of GIPA/MEPA in discussions. For many, these tenets were political beacons and reminders of why they did the work they did.

In image 1c, Chantal, a peer worker, physically extends her hands with the agencies logo scribed upon them, in a gesture of support, or as if presenting a path forward. In another photo narrative (meant to accompany photo 1c, not pictured) Chantal shared many of the hardships she had experienced, prior to finding "PWA as a 'family for everybody.'" She wrote about the "emotional, mental, physical, and spiritual support" PWA provided, and her desire to help "other women and girls who are HIV positive to get out of isolation, stigma, and discrimination and make a better life." When accompanied with photo 1c, we see hands displayed as if an offering, towards a future path on this journey. She writes, "I stopped crying and started a new life moving forward … I have become an activist, an advocate for others - people living with HIV/AIDS without discrimination of age, education, gender, sex[ual] orientation and religion." Here, Chantal's personal journey of hardship motivates her larger engagement within PWA as a volunteer, and activist. For her, taking these photos was a form of advocacy. When speaking to her other photo, she proudly proclaimed, ""I took this photo as advocacy [….] to make a difference."

As the demographics of who is most impacted by HIV in Ontario have shifted overtime, PWA has become more inclusive to diverse communities – in particular, women living with HIV (many of whom are racialized), and newcomers. PWA participants reflected on the organization's

journey, and their active role in changing organizational culture – in particular, shifting who was publicly visible. Andrew, speaking about the history of the organization as a white, gay man, commented:

> there is a perception that PWA is a white gay men's organization and I really, really bristle at that because I've been in this movement for really long time. […] It pisses me off because there were women of color in this organization when it was being founded. There were straight men […] there were lesbians. You know, to disappear all these people from our movement…

Several participants reflected on how they actively disrupted this perception by welcoming many communities living with HIV into the organization. This was exemplified photographically by hands gesturing towards a path forward (photo 1c) and through proudly advertising a sign with the multiple languages volunteers spoke (e.g., English, Swahili - photo not pictured).

Volunteers also participate in organizational committees. As one volunteer, Yvette, shared about Pride celebrations: "We are encouraging all the volunteers to get involved. I am not gay, I am not a man, but I get involved. […] So, me being out there as a coloured woman, African and supportive of that…." For Yvette, these same principles applied "during the Black History month, [that] only the Black people are there. No, we don't do that." Participants did not see themselves as apart from PWA, but rather, as key players (and advocates) within the organization's journey.

"New ideas, emerging as a different person": Journey as growth and struggle

Out of Empower's 18 exhibited photos, slightly less than half of photos represented journey. Similar to above, photos referencing accessibility and support, or peer leadership and advocacy were also common, suggesting a relationship between personal and collective journeys, and participants' roles as peer educators advocating for larger structural change. Many participants chose to visualize journey through flowers or plants in various stages of growth, from pre-germination, to growth, to decay (figure 3 – photos 2 a,b,c). In photo 2a, titled "emerging", '2 bite brownie' captures a plant from a birds-eye view perspective; the green grass sprouts into the frame

towards the viewer. She writes: "this photo captures the growth that comes with finding your own voice in Empower or other supportive youth program[s]. Emerging more authentically into someone we're always meant to be." Commenting on her image, 2bite brownie expressed: "I feel that's growth, finding your voice or reclaiming your voice. [….] I think that the more you give yourself permission to shine, the more you give others permission to do that as well."

However, growth, for 2bite – like many participants – was not always easy; it came in the context of tremendous struggle. In comparison to PWA, where participants spoke to overcoming challenges in the past, Empower participants spoke openly about current challenges they encountered as young people, such as mental health, racism, poverty, or transphobia. They frequently made recommendations for creating more accessible, equitable and supportive youth-led programs for youth who experience marginalization. Growth at the site of struggle was most strongly visualized in photo 2b, depicting a pot of soil (entitled "growth"). As Lydia expresses, the seeds dropped in the pot must undergo "changing and severe" temperatures as a part of the growth process. However, with time, and "when left in peace, given food and light. Respectfully left on its own. And given time to settle" the seeds may "sprout, quickly growing."

This idea of journey was both a personal and political process, undertaken with the support of others. As Michelle told us (who also photographed a plant – not pictured): "Empower helped me get more in tune with myself." She explained that she "was able to connect" with herself because of the relationships she created, and because she was "doing meaningful work." In Empower, youth go through an extensive training program towards designing and delivering community-tailored, arts-based HIV prevention workshops. Part of this process involves connecting personal experiences to larger structural issues. Many participants saw their personal growth (and struggle), as connected to their role as peer educators. For many, the personal was

political. As Buttercup expressed: "[In] other spaces, you see these idealized pictures of what youth potential looks like. With this space, we reflect on what our struggles are and how we're using our experiences to empower ourselves through community, and conversations where we're imparting something to other folks."

However, this often came with a cost. At Empower, participants overwhelmingly spoke about the emotional impact of this work -- battling systems of oppression, burn-out and the burden of fighting for social change with limited resources, was often expressed as a loss. This was unique to this site and is explored elsewhere (See: *Youth Talk Back*).

Buttercup visually expressed these hidden costs through an image of wilting flowers (photo 2c). She wrote:

> As an advocate that is committed to raising awareness to issues that impact marginalized youth; my understanding of engagement would be incomplete if I didn't think about the people who are actively working towards social change. I thought about some of the personal challenges. Like a rose that is so beautiful and vibrant in the beginning. As time progresses, without proper care and without being grounded, it wilts. The wilting resonates with my feelings of being burnt out; feelings of distress and agony that often comes along with doing this community work and challenging social norms.

Her warning is poetic and powerful. As she continues, we must ensure "sustainable supports so folks do not become burnt out and can continue to work progressively in HIV prevention, sexual health and harm reduction programs." With "the proper care", and equitable conditions, these "seeds of our labour" (the image's title) might sprout like other plants in figure 3. Here, the discourse of GIPA/MEPA was mostly indiscernible - even though some youth within the program were living with HIV.

"We're moving on to new beginnings:" Structural supports and the journey towards health

At Casey House, the hospital was depicted as a place where clients worked to stabilize their health. Out of 29 exhibited photos, over half represented journey. Here, most journey photos were

simultaneously coded as honouring relationships – something that was unique to this site. The theme accessibility and support – as was the case at all sites - was prominent. Unlike the other sites, there was no unifying visual metaphor signifying journey. However, nine photos (half of the journey photos) visually referenced structures: furniture, or images of the interiors, or facades of buildings - including Casey House itself (figure 3 – photo 3a,b). In two cases, staff photographed built roads or highways (photo 3c). One client photographed a transit system, and referred to "opening doors" when discussing his photo.

For many, the visual attention to structural supports served as symbol for re-building hope around health. With treatment advances and increased access, the HIV epidemic is now a chronic condition (for many in Ontario), and many individuals saw their health journey as intersecting with the organization's journey from hospice to hospital. At the time of the study, the hospital was undergoing a second transformation. By the end of the project, clients would move from the 13-bed hospital (in a physical house) into a much larger, 58,000 square foot purpose-built facility, with a new day health program designed to provide enhanced community supports and services. In figure 3 (photo 3a), Brenda collages an image of doors inside the old hospital building with an image of the porch, overlooking the new facility across the street. The new building is literally and metaphorically on the horizon. As Brenda writes, "That's the door … when I come through I know there's friendly faces there. And that's the heart, and the new building. […] It's living, not dying, walking through the door. There's a new beginning over there." Many clients took photos of this building to signify "new beginnings," and referenced the concept "living not dying."

The emphasis on "living not dying" must be understood historically. A staff member, Joanne, relayed a story from a client that illustrates why physical structures and reflections on the new building were resonant: "Knowing how [. . .] the epidemic has consciously changed

somebody, how strong the impact may be on them, you know? […] He said that, 'I see the rooms where my friends died'. He said, 'you know instead, I look across the street and I see life, I see hope and I see forward movement... memories and feelings associated with these walls." Many clients spoke evocatively about their own mortality, past or present experiences receiving care, or, losing loved ones at Casey House. Robert's photograph (photo 3b) shows a desk where individuals come to pay their respects to those who have passed. On the desk, a candle is lit to mark this passing. As Robert's narrative expresses:

> I love seeing the candle *not* lit but there's times when I like to see the candle lit, because I know the person isn't suffering any more. So, there's been some sad moments at that chair for me, you know. …. For me, that's Casey House right there. …. People used to come here to die, and people are leaving out the front door now.

This photo accompanies another photo of the building where he reflects on his journey, health and mortality. Physical structures, and the memory of the house, was so instrumental to participants understanding of engagement that they chose to build a replica of the old hospital, designed from participants' photographs for our final installation (see: *New Directions for Photovoice*). Participants were morning the loss of their relationship with the old house, as they journeyed into the new building. Over time, clients had created deep interpersonal relationships at the house; they told us about the friendships and informal support networks they had forged over years.

In contrast to other sites where participants saw their role through a professionalized or politicized lens, participants spoke to their roles as either clients undergoing a health-care journey, or those supporting this journey as administrators, service providers, coordinators or clinicians. When clients did speak to participating in decision-making processes, like community consultations, it was often through the language of "giving back" or a reciprocal exchange – especially when their health had stabilized. As one client expressed, Casey House "has given me

so much, they've been like angels to me. I don't feel like I owe it to them, but I want to contribute to make it better for the next person who stays here or helping somehow."

This emphasis on organizational relationships was also reinforced by staff members, who often spoke to engagement as it related to a service-provider/client relationship and supporting people to meet health goals over time. Andra, a nurse, depicted a highway to represent the journey of communication with her titled photo (3c), "open road, open dialogue." As her narrative expressed: "client engagement is a journey that we navigate without the help of a roadmap. The empty and diverging highways in this photo remind me that there are many routes to engaging clients in their care, but that promoting open and honest lines of communication – like this open road – is always a good place to start." As she explained, these journeys took place over time,[2] and staying on the journey even when it wasn't easy, "during roadblocks" and "traffic jams" was an important part in the process.

These are different metaphors when compared to the other sites.[3] Taken together, they suggest that engagement at Casey House is often connected to one's health care journey – in particular, receiving or providing care - rather than advocacy, peer leadership or social justice, as more commonly discussed at other sites. For example, approximately one tenth of this site's photos fell into the theme of advocacy, compared to almost half of the photos from other sites. Here, the discourse of GIPA/MEPA was also not very common. When referenced, it was usually by staff, or by those who were more actively involved in ASOs. Some had never heard of the principle.

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[2] The average stay is 45-65 days, and can be re-occurring.
[3] While one might attribute the difference to season, participants at this site took photos in the spring, and many other photos were taken outside.

This was also the only site that did not have an active peer-led program at the time of the study.[4] Many clients have fluctuating physical, cognitive, and mental health challenges that make a traditional peer-programming model more difficult. Nonetheless, for many, the integration of peer-programs holds promise. Brenda echoed the importance of relationships and 'giving back': "I can volunteer at church or anything else like that, but this place is important to me... Right now, we want to be in charge in a group. … And it is important to keep myself busy and focused. […] We need each other. […] My thing is to always talk about peers helping peers." Some clients expressed that the strength of organizational relationships, and accommodations for fluctuating health and access needs made Casey House more "engaging" than ASOs. As the organization continues its own journey, both staff and clients spoke to the potential of developing a unique model for peer leadership in a clinical setting.

Discussion

In this article, we explored how participants at three sites providing HIV programming and care made use of journey metaphors when discussing engagement. Journey is a common metaphor within health, where there is a cultural and social history of metaphoric thinking about the body (Kearns, 1997; Sontag, 1978, 1988). In cancer research, metaphors of journey are often referenced as a way for individuals to make sense of their struggle (Harrington, 2012; Semino et al., 2017).

Within HIV organizations, individuals living with, and impacted by HIV come from many different communities, and hold intersecting identities associated with gender identity, race, indigeneity, sexuality, ability, citizenship, class, drug use experience, and health status. These experiences and intersecting identities all impact people's journeys, as well as their desires and

[4] Casey House had begun preliminary consultations to develop a peer-led programming, including potentially adapting their volunteer program to include clients.

motivations for involvement. Considering people's varied desires for involvement – or in other words, their personal journeys - may help organizations more effectively design engagement strategies that leverage people's experiences in meaningful ways, so organizations can *journey together* with the communities they serve.

Our findings are consistent with other studies that show that people's motivations to participate will vary within an organization or project (Flicker, 2008; Fry, 2008; van der Velde, Williamson, & Ogilvie, 2009). In our study, the socio-political context(s) of our sites, and participants' roles within them, impacted how participants understood engagement, and the possibilities therein. For example, at PWA – a service-oriented organization – participants saw engagement as inspired by their own journey around disclosure, acceptance, and anti-stigma, and their role in directly supporting others within PWA on their path towards healing. At Empower – a peer education project – youth saw their journey of growth as a way to politicize their lived experience, and mentor other young people to do the same. At Casey House – a hospital - participants saw engagement as connected to their healthcare journey and the relationships formed between clients, or clients and staff. This is consistent with literature that explores how socio-political contexts of host-organizations will influence on how people understand their involvement (Cohen & Uphoff, 2011; Flicker, Savan, Kolenda, & Mildenberger, 2008). Before organizations try to figure out how to 'do' engagement, they may benefit from asking stakeholders how they understand it.

Organizational priorities will also shape the possibilities for what is considered meaningful for those involved (McClelland et al., 2018). For example, in our study, organizational cultures, priorities and current programs/services likely influenced what participants chose to visually represent, as well as how they understood the possibilities therein. At PWA and Empower,

participants spoke evocatively about peer leadership and advocacy, in part because their organizations and projects were informed by these principles. In contrast, at Casey House participants tended to focus on relationships or care rather than peer-involvement in organizational decision-making. This resonates with literature on 'patient' engagement that often focuses on the individual health impacts of engagement rather than on the relational or organizational processes that sustain it (Barello, Graffigna, & Vegni, 2012)**.** This may help to explain why at Casey House, some participants struggled to articulate understandings of engagement that did not rely on service-provider/client dichotomy. This is not to suggest a hierarchy of participation (there are many valid reasons including ill health which may limit possibilities for involvement) however, our findings suggest that organizations may benefit from the conceptual opportunities of imagining different possibilities for peer roles.

The language of journey may also be a site for individuals to make meaning out of (shared) experiences, build relationships, and identify new opportunities for collaboration. Our process was very much like a journey; many participants reflected on how much they appreciated being able to take, discuss and exhibit photographs, or "visually-story" (Schrader, Deering, Zahl, & Wallace, 2011) their lives and experiences. It was through the process of collectively discussing engagement that people could identify individual and collective journeys towards healing, growth, and sense of purpose that otherwise might remain hidden.

Journey evokes temporality – it implies a past, and a future, and change over time. Our findings show how participants understandings foregrounded engagement as a dynamic, relational, and temporal process, rather than a fixed outcome (an end), or an instrumental means. If organizations see engagement through the lens of journey, they may be more attuned to understanding stakeholder's various roles in shaping this journey. Rather than something 'done'

to a community, engagement becomes a space where we might 'journey together' to some unknown end. To paraphrase Horton and Freire (1990), the road is "made by walking." In other words, *how* we journey together may change our route and destination altogether.

Nonetheless, this does not mean that journey must follow a linear, future-oriented trajectory. At Casey House, although many participants reflected on past experiences at the hospital, and spoke about the "new beginnings" ahead, when it came time to exhibit their work, participants chose to build a replica of the *former* hospital out of photographs. We spent many weeks discussing the past while building this house. At that time, participants had no desire to journey 'forward.' It seemed, instead, that they preferred to stay in the intimacy of the old, cracked bricks and peeled paint instead. They built the house "so that no one would forget."

Journeys are not always smooth. They may be bumpy. Power dynamics between people in different roles, and within institutions may create conflict or tension on these journeys. Importantly, dynamics of race, class, gender, sexual orientation, and drug use experience, are all forms of social difference that may come up in encounters between people in organizations. As Ahmed (2000) writes: "If we think of the encounters socially - that 'being' only emerges through and with others than we can think about how meetings between particular others do not necessarily presuppose a meeting between two already constituted beings" (144). This means that it is only *through* the journey that both individuals and communities are created.

For example, at Empower, many participants spoke to complicated feelings of growth, as bound up in struggle. These experiences often had to do with navigating burn-out, and the 'call to participation.' These experiences were understood through intersecting factors of race, gender identity, ability, and/or class. At PWA, women of colour actively made themselves visible as volunteers on committees and at reception desks in order to welcome a more diverse community

into the organization, thus intervening in the larger public narrative of an HIV movement led by primarily gay, white men (Wilson, Flicker, Restoule, & Furman, 2016). At Casey House, participants alluded to the tensions that may exist in a small space amongst those struggling with their health, and larger socio-structural issues (i.e., poverty). The challenges of sharing a clinical space between those who use drugs, and those who do not, has been addressed by a sub-set of those on this research team (Strike, Guta, de Prinse, Switzer, & Chan Carusone, 2014). It is important that the metaphor of journey for understanding engagement, does not wash over these important differences, but rather, becomes a site for developing new forms of relationships.

Last, because engagement is an abstract, "fuzzy" term that often morphs across contexts (Head, 2007), journey may provide a concrete, and narrative site for people to share their experiences, motivations, or desires for engagement within and across the HIV sector. As discussed earlier, studies on engagement within the HIV sector tend to focus narrowly on GIPA/MEPA within particular ASOs or in community-based participatory research contexts. Our study looks *within* and *across* different organizational contexts (including an HIV prevention program, and a hospital) to explore stakeholder's subjective understandings of engagement. Our findings showed that although it is an important principle, GIPA/MEPA does not always translate outside ASOs. However, the theme of journey resonated at all sites, thereby suggesting that a conversation about engagement vis-à-vis journey may allow us to speak to engagement in more inclusive terms. Journey brings everyone's experiences across the sector into dialogue with one another, however differently constituted.

Table 2 summarizes many of the issues discussed above, and presents a series of questions that illustrate how journey might be utilized in discussions within organizations.

1. How might leveraging the metaphor of journey create spaces for individuals to reflect on their experience of engagement within an organization? In doing so, how might this open new opportunity for future collaborations, or directions?
2. What is your organization's journey? How have communities shaped this historical narrative? Do community members have the resources and power within an organization to intentionally shape this narrative moving forward?
3. When engaging people with lived experience in programs and policy change, how do organizations nurture relationships so people can 'journey together'?
4. Whose voices, and which bodies are visible in your organizational journey? How is this shaped by contours of gender identity, race, class, poverty, indigeneity, drug use experience, etc.?
5. Individual and organizational journeys may involve loss and grief. How do organizations support its stakeholders through transitions, or with experiences of loss?
6. Given the weight of structural barriers and systemic oppression, how do organizations better support peer workers and volunteers who may experience symptoms of burn out on their journeys?
7. Attending to the voices of communities affected by an issue will change the structure, culture and direction of an organization. Are organizations prepared and willing to take this journey?

*Table 2 – Questions for organizations on journey. (*Adapted from: Switzer et. al, 2017).

Limitations

While our study offers many insights, there are some challenges. First, as an abstract term, engagement sometimes required prompting from researchers to help participants with the task at hand. While most participants could understand the task with little support, some participants – especially those with intellectual disabilities, cognitive challenges, or language barriers, required more support. Wherever possible, we used examples from group brainstorming activities to help support this process. In some cases, other participants stepped in to provide support. This may have introduced a 'group think' mentality or social desirability bias for some. However, because we met multiple times, we attended to emerging ideas over time.

Second, sites were HIV community-based organizations or projects with a service delivery, or health promotion mandate. While there were many reasons we selected these sites as cases (as discussed above), the contexts of the organizations framed how engagement was discussed and

understood. Had one of the organizations been an advocacy-based organization, we may have heard different understandings. Future work might want to explore how these understandings differ in advocacy-based organizations.

Third, our analysis is focused on participants' *exhibited* photographs – in other words the photographs participants intentionally prioritized for uptake by a wider audience. This allowed us to foreground participants' voice (through metaphor and their narratives) and their interpretations (through discussion and analysis). Nonetheless, there are some challenges with this approach. An analysis of exhibit-only photos excludes other photos that participants took and discussed. Because of the depth of involvement of the photovoice method, most participants at PWA and Empower were only able to discuss up to two of their photographs in group sessions. In most (but not all) cases, the same photos that were discussed, were chosen for exhibition. However, at Casey House, because we discussed photos via interview, participants could discuss significantly more photos than at the other sites. It is outside of the scope of this article to explore the differences between exhibited photographs and non-exhibited ones. However, it is likely that the small sample size, participants' desires to be credited for their work, and their relationships to partner organizations, may have dissuaded participants from sharing challenging views in a public venue. As such, by focusing only on exhibited photos, our analysis may present a less critical view.

Fourth, community-based participatory research approaches involve working closely with community-based organizations throughout all stages of the research. This has profound opportunities for research relevancy, rigour, and trust building (Flicker, 2008; Wallerstein et al., 2017). The lead author also had relationships with all the sites, which likely coloured her perspectives. This is less a limitation, than an acknowledgement of her partiality – a factor in all qualitative research. We attended to this issue by including research team members with more

distance from the sites in the analysis process; inviting community investigators (who had familiarity with the workshops) to share their experiences; and asking participants to identity challenges encountered in organizations during data collection.

Last, there are some limitations with our analysis by site, and role. Although we consulted a diverse pool of program participants, peer workers, and peer volunteers (i.e., role and social identity), we intentionally consulted fewer staff (those *not* hired into 'peer' roles), in order to prioritize voices of community members in our study. However, this resulted in a reduced diversity of staff perspectives, in terms of professional role, and social identity. Additionally, with the exception of Casey House where staff/client roles were distinct, at other sites, there was less discrepancy between roles, as participants occupied different roles over time. For this reason, analysis of roles within PWA and Empower was not possible.

Despite these limitations, thinking through engagement via journey holds promise, especially for discussing the more dynamic, or relational elements of engagement. An analysis of journey within and across organizations illustrates how engagement must be considered in relation to organizational context, and the roles that people play within them. How people perceive their roles as connected to organizations, and their journey within them, may shape the material and conceptual possibilities for engagement within the HIV sector.

Conclusion

We believe that HIV community-based organizations cannot exist without the insight, passion, and experience of people living with and affected by HIV, at the forefront. Looking across and within three diverse settings illuminates the ways in which journey might serve as a productive metaphor for thinking about engagement as a process rather than an end or a means. Rather than seeing engagement through a list of facilitators or barriers for involvement, journey allows us a

rich site for stakeholders in community-based organizations to make sense of their subjective experiences of engagement. Journey also provides a generative site to ask: How did we arrive here? Where do we want to go, as individuals? Where do we as an organization want to go? And, how can we go 'there' together? While this journey may sometimes be bumpy, it has the potential to be transformative – for individuals, organizations, and the HIV sector as a whole.

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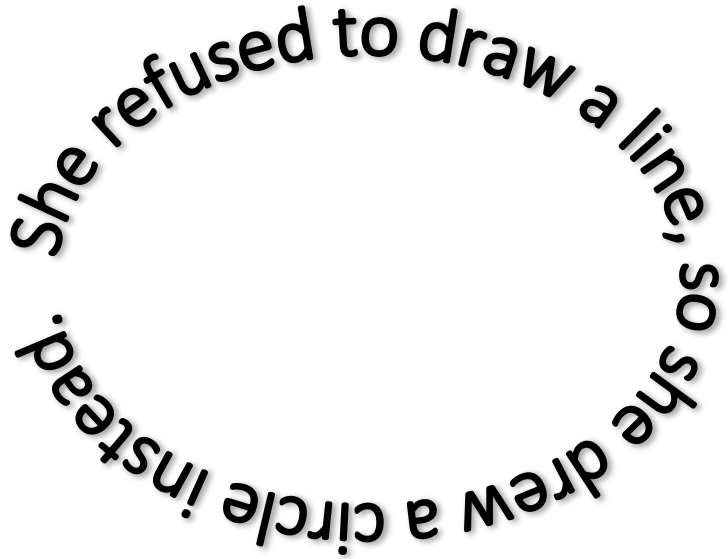

[1] In 2017, I crafted a long-form poem out of pediatric medical notes. The poem contains direct transcripts from neurological assessments conducted after an acquired brain injury I sustained as a teenager. In these notes, a psychologist ascertained that my ability to read and draw images (as well as keep up with academic demands) had been permanently compromised. He based this decision on a series of neurological tests. In one of these tests, I was asked to copy a design with lines. I deviated from his instructions, and failed. Thinking through my personal episodic experiences with disability and queerness as a young person was a key entry-point into my interest into non-participation, and willfulness. As Ahmed (2014) writes: "Assembling a willfulness archive is a way of attending to histories that are kept alive by forgetting" (p. 67). In this poem, I speak to the opportunities and consequences of this willful deviation. The above visual is a reference to this poem.

Chapter Four[1]

"People give and take a lot in order to participate in things:"

Youth Talk Back -- Making a Case for Non-Participation

Introduction

In this paper, I productively theorize non-participation by putting photographs and narratives produced by youth in conversation with critical scholars' writing on settler-colonialism, neoliberalism, and willfulness. I argue that young people's refusals to participate (or to participate in ways that make sense to them) are an act of resistance that challenge and disrupt normative approaches to participation in youth work.

From the Young Lords and Black Panthers of the 1960's and 70s, to more contemporary social movements like Idle No More and Black Lives Matters, young people have been at the forefront of social justice organizing. However, the adult dominated social service sector has not always recognized the potential of young people to affect social change. The deficit-based social welfare model framed youth as people needing to be fixed. This began to shift in the 1980s as the youth sector became interested in 'positive youth development,' and re-framing young people as provisionally capable and agentic. Prescriptive scripts that aimed to 'empower' 'at-risk' young people became the sector norm (Kwon, 2013). However, in this newer model, youth were constructed as 'pre-adults' (to be governed, or fixed by youth development), or romantic leaders of tomorrow (in contrast to being seen as people actively resisting today) (Ginwright, 2008; Kelley, 2014).

[1] This manuscript will be submitted to a journal in education. It is sole-authored.

By the early 2000's, funding calls for *youth-led* programming – programs run for and by young people – were on the rise (Parris, 2018; Youth Speak Out Coalition & Zimmerman, 2007). Many of these youth-led spaces bare traces of self-organizing reflected by social movements. In many cases, these projects may re-distribute power, and build alliances between youth leaders and adult allies to organize across sectors and movements (Fox et al., 2010; Fox & Osato, 2018; Switzer et al., 2016; Tuck et al., 2008). Nonetheless, as Cornwall (2008) argues "opportunities to participate […] whether in response to statutory obligations or their own initiative … are often structured and owned by those who provide them, no matter how participatory they may seek to be" (Cornwall, 2008, p. 275). This makes youth-led programs a unique site for investigating the way in which the 'call to participation' operates in programming and participatory research.

In youth-led projects, the rhetoric of participation often constitutes youth subjects as free to choose and act as 'empower-able' individuals in participatory processes (Kwon, 2013). Drawing on Foucault's work on governmentality, scholars have traced how neoliberal discourses of the rational, free actor have played out through the rhetoric of willing, voluntary participation (Dhillon, 2017; Guta, Flicker, & Roche, 2013; Kwon, 2013). For many, participation has become yet another accessory of neoliberalism – as another strategy to control and manage unruly bodies. Here, neoliberal policies shape discourses that promote individual responsibility while reducing funding to social welfare, and discouraging approaches that might challenge state-created inequities (Brenner, Peck, & Theodore, 2010). At the same time, structural factors that may impede young people's participation get erased under the guise of individual responsibility, capacity-building and the language of eradicating 'risk.'

The 'call to participation' also neglects many of the valid reasons young people choose not to participate (Low, Brushwood Rose, Salvio, & Palacios, 2012; Milne, 2012). For many youths

who are navigating systemic oppression on account of race, gender identity, sexual orientation, ability and/or class, participating is not always desirable, or an option that they feel 'free' to choose. Many of the young people I work with in youth-led initiatives negotiate these complexities by actively choosing to opt-out of participating either permanently or temporarily – what I (and others) call non-participation. Sometimes their proclamations are active and direct. Other times, they function more like "hidden transcripts" of resistance (Scott, 1990) masked behind indirect claims: *Nah, no thanks. I think I'll pass. I'm gonna' go for a smoke. I have to leave early.*

Common typologies frame youth participation as something that exists at different hierarchical levels. Roger Hart's Ladder for Children, or Youth Engagement (1997, 2008) -- modelled after Arnstein's Ladder for Citizen Participation (1969) -- labels the bottom levels of the ladder (manipulation, decoration, and tokenism) as non-participation. Shared control, and decision making are at the top. In the International Association for Public Participation Spectrum, participation begins with involvement, and ends with empowerment. Scholars have critiqued these typologies for ignoring contextual specificities and the complexities, nuances, and power dynamics inherent in participatory processes (Chiu, 2008; Cornwall, 2008; Tritter & McCallum, 2006). As Cornwall (2008) argues, while participation typologies "differentiate kinds of participation, they do not tell us much about the different kinds of participants who take part in community development projects. The question of *who* participates – as well as *who is excluded* and *who excludes themselves* is a crucial one" (p. 275, *emphasis added*). Cornwall also notes that these typologies do not account for self-mobilization (which may or may not challenge power structures). In all cases, it is telling that non-participation is positioned either as something negative (i.e., at the bottom of the ladder), or not addressed at all.

These typologies are frequently cited in community and youth engagement frameworks,

policies and toolkits. Their prescribed, linear framework (and focus on citizenship) reveals the teleological nature of the 'call to participation,' which can be traced to positivist and behaviorist traditions within education and health. These traditions – and their contemporary manifestations – can be linked to settler colonial theories of change that "prescribe and proscribe the direction of change from oppression to liberation … or from bewildered to enlightened" (Tuck & Yang, 2014b, p. 522). In this progress-oriented theory of change, those 'doing the engaging' are positioned as bearers of democratic ideals working towards a greater society, and those participating are presumed to be 'improved' because of them. When we think about young people, and the intersecting axes of gender, race, indigeneity, ability, and class, alongside the histories of youth work (Dhillon, 2017; Fox et al., 2010; Kwon, 2013), new questions emerge: Who are the presumed subjects in these typologies? Which bodies are positioned to be 'empowered' and fixed?

Furthermore, discourses that construct participation as a moral imperative may imply that that the primary goal of marginalized communities is to make themselves more intelligible and available to those in power (Low et al., 2012). When participation is articulated as a desired state, individuals who choose *not* to participate (or fail to participate properly) can be positioned as irresponsible, deviant or acting outside of their own or community's best interests. The costs and benefits of participation fall differentially (Flicker, 2008). Is it possible that people may be making a choice *not* to participate? Often, young people have legitimate reasons for their refusal. What happens when these young people refuse what is a seemingly 'good' thing?[2]

In this vein, I turn to non-participation - what it means to actively *not* participate and what non-participation might engender for thinking about and enacting participatory processes with young people. Herein, I define participation as the *act of taking part* in organized activities, and

[2] Here, I draw inspiration from Simpson (2014). I will return to the politics of refusal later.

the implicit or explicit expectations that come with this act. To take part, as the etymology of participation reveals, is to acknowledge a relationship with a larger whole. This is important, because participation is never neutral. People do not participate 'just because' – they are often *willed*, (Ahmed, 2014) or called to participate. Participation in institutional contexts always comes with an invitation (Cornwall, 2008). In contrast, I see engagement as including the act of participation, as well as how people subjectively understand the experience. Engagement also includes how participatory activities or programs – often tied to state-funded institutions (schools, non-profit organizations, governments, universities) - are contextually understood, as well as organized, facilitated or mobilized either within or against the neoliberal, and settler-colonial state.

In advocating for a desire-based framework, Unangax scholar, Eve Tuck (2009) argues that we need more frameworks "concerned with understanding complexity, contradiction, and the self-determination of lived lives (p.416)." Desire-based frameworks are also incongruous with the behaviorist theories of change that are implicit with the participation typologies discussed above. In this paper, I draw from narratives of young people from the *Picturing Participation* photovoice research project to productively theorize non-participation. As part of this study, I asked stakeholders at a youth HIV prevention and harm reduction program to take and discuss photographs that reflected their ideas about engagement. Elsewhere, I describe how youth explored these ideas (Switzer et al., 2017). Here, I delve into the way in which they understood their participation as constrained, and what it meant for them to actively *not* participate. Using a desire-based framework, this paper provides a thematic analysis of how young people understood and navigated this 'call to participation' in complex, and self-determined ways.

Following this, I put their narratives in dialogue with critical scholars' writing on settler-colonialism, neoliberalism, and willfulness to tease apart why and how young people's comments

on non-participation offer a sophisticated counter-hegemonic understanding of this 'call to participation', and its discursive and material effects. For the purpose of this paper, I see settler colonialism as a structure that informs institutional practices and discourses rather than a discrete historical event (Wolfe, 1999). Similarly, as Coulthard (2014) asserts, "settler-colonialism should not be seen as deriving its reproductive force solely from its strictly repressive or violent features, but rather from its ability to produce forms of life that make settler-colonialism's constitutive hierarchies seem natural" (p. 152). While these are separate and distinct processes, both neoliberalism and settler colonialism function in increasingly invisible ways through a "fluid confluence of politics, economics, psychology and culture" (Alfred, qtd. in Coulthard, 2014, p. 48).

Taken together, participants' voices bolster the recent work of scholars who have questioned the discursive role of participation in enacting neoliberal strategies of surveillance and control (Dhillon, 2017; Guta et al., 2014; Kwon, 2013) – in other words, what is at stake when one is invited to *willingly* participate in processes that may appear voluntary (Ahmed, 2014). As Ahmed (2014) asks, "What does it mean, what does it do, for the participation of some to be dependent on the invitation of others? When participation depends on an invitation, then participation becomes a condition or comes with conditions" (p.53). Participants were aware of these conditions, costs, and constraints.

Last, drawing on the work of many Indigenous theorists who advocate for a politics of refusal (Coulthard, 2014; Simpson, 2014; Tuck & Yang, 2014a), I argue that young people's refusal to participate (or to participate on their own terms) may actually be an act of resistance – especially for young people whose bodies are surveilled, and regulated on a daily basis. The politics of refusal originates with Indigenous communities fighting for political sovereignty; in

inverting the script, this refusal "raises the question of legitimacy for those who are usually in the position of recognizing" (Simpson, 2014, p. 11). As a settler, it is important that I do not wash over these origins. These politics operate in specific conditions, with specific nations, and on specific lands. However, the politics of refusal also has implications for broader communities - especially those who have been heavily researched, and/or involved with the non-profit system (which has its own colonial legacies). I conclude by joining with youth to make a case for non-participation as way to disrupt, or rather, refuse hegemonic, linear theories of change employed by common participation typologies, and invite practitioners, researchers and educators working with, and alongside young people, in the spirit of social justice to do the same.

Methods

Overall Study Design

The data and analysis for this paper is embedded in a larger community-based participatory research study (Minkler & Wallerstein, 2008) study, *Picturing Participation: Exploring Engagement in HIV Programming, Service Provision and Care*. Community members, organizational staff, and academics partnered to design and execute the study, and disseminate findings as discussed elsewhere. The team used a case study approach (Yin, 2003) and photovoice (Wang, 1999) to explore how stakeholders understood engagement within and across three HIV community-based organizations. This paper focuses on findings from Empower – an entirely youth-led HIV prevention and harm reduction peer education program that was in operation at a local community health centre from 2010-2016. In Empower, youth program participants and mentors design and deliver community-specific workshops; youth mentors are hired (usually from past participants) to recruit participants from their communities, and support the workshop design

process. I initially founded the program as a young person. While I transitioned out of the role of program coordinator in 2014, I have maintained an ongoing relationship with many of the participants. I now work with many of these young people in various roles as co-researcher, mentor, and sometimes colleague (Switzer et al., 2016). These relationships have profoundly influenced, marked, and altered my work and life, beyond my doctoral studies.

At the time of the study, the program was currently on-hold due to loss of funding. As a result, eligibility criteria for the study included experience as either a *former* program participant, youth mentor, or program coordinator. Because young people in Empower moved into different roles over time, many had held multiple positions in the program, and were active in the larger community. At the time of the study, all 11 participants were between the ages of 22 and 29. Participants predominately (although not exclusively) identified as gay, bi-sexual, queer, or two-spirit. Many were trans identified, or did not identify with binary classifications of gender. Youth were affected, interested in, or in some cases, living with HIV. Slightly over half of the participants were youth of colour. Some were Indigenous. Many identified struggles with mental health and/or having an invisible disability. Some youth participants identified having drug use experience, including past active, current recreational, or chronic use. All were passionate about the work they did as peer educators; many had experienced disillusionment with traditional education systems.

Photovoice Workshop Design

We used photovoice (Catalani & Minkler, 2010), based on the work of Wang (1999). Photovoice is a method where participants are given cameras to identify, discuss, and analyze issues – and in our case ideas – in their communities. It usually takes place over time, with groups, and pairs well with projects that have a strong program or policy change component. Our process included seven audio-recorded workshops that were co-facilitated with the former project

coordinator. I also conducted two photo-elicited interviews with participants who were not able to make select workshops. Over two months, participants were asked to take and discuss photographs that captured their understandings of engagement. We brainstormed ideas and discussed photography fundamentals and ethical issues. Participants received a camera, honorarium, and handouts with guiding principles (e.g., no pictures of people without verbal consent, there's no way to do this wrong), and optional sub-prompts generated with help from research team members (who were also young people connected to Empower). Each participant chose 1-2 photos for analysis and exhibition and wrote accompanying narratives and captions. (Captions used in this paper reflect these choices). We also planned how to exhibit our work together. A more in-depth discussion of our methodology can be found elsewhere (See: *New Directions for Photovoice*).

Analysis

As part of the photovoice process, participants collectively looked across their photos to identify common themes. Actively choosing to 'not participate,' 'opt out,' or 'take a break' was a recurring theme throughout our discussions. Youth articulated the common thread of 'struggle,' 'growth/purpose' and 'burn-out' as expressed throughout many of the photos. Later, over multiple meetings with representatives from other sites (including Empower) we refined themes into a coding-framework using the DEPICT method. Coined by Flicker and Nixon (2014), this collaborative analytic method seeks to improve analytic rigour by creating an accessible way to including multiple stakeholders in the analysis stage. It was through iterative dialogue that participants' ideas, as expressed throughout this paper, were refined under the banner of 'non-participation'(Switzer et al., 2017). Photos from the project were coded, and while present at all sites, the theme of non-participation was most dominant at Empower.

To conduct this *site-specific* thematic and visual analysis, I carefully reviewed the

Empower photos and narratives coded for non-participation during our collaborative analysis meeting. I also coded and analyzed workshop transcripts and field notes to tease out how this phenomenon was further discussed. Quotes are taken from transcripts and narratives. Based on the work of Drew and Guillemin (2014), this predominately researcher-driven analytic process looks across five analytic sites -- the researcher, the participant, the image, and the context of its production and the audience/s -- and balances participants' interpretation of images, with the researcher's ability to look across the data set, and literature. In keeping with our collaborative approach, draft findings of this article were shared with a sub-group of Empower participants for further discussion and refinement. Participants chose their own names. Many are pseudonyms. I also had many informal conversations with participants, and research team members affiliated with Empower about this topic over time.

Findings on Non-Participation

During one of our workshops, I asked participants to look across our photos, reflect on past conversations, and record key ideas on sticky-notes that were important to share with others designing or delivering youth-led programming. After doing a gallery walk around the room, they worked in groups to post the notes onto the board [figure 1].

Figure 1 – Selected notes

The following section extrapolates on these early ideas, and draws on participants' experiences participating in, and sometimes leading youth-led programs across the city.

"The Hidden Costs of Participation": De-Bunking the Romance

Our conversations signaled that participants were well-aware of both the benefits, and constraints to participation – what they called "hidden costs." Some of these costs included feeling uncomfortable when discussing certain topics, negative impacts on mental health, or breaches in confidentiality. For example, Two Bite Brownie told us about having her confidentiality breached around sex work when attending a youth program. She was 'outed' by another program participant. She shared how difficult this experience was for her, and how she felt it was up to her to "control [her] own narrative." This can be a risk when participating in group programs which require identification around a shared experience or being hired into a peer role. While confidentiality may be guaranteed by agency staff, it is not always assured by others.

For this reason, many saw their participation as something they actively negotiated on an on-going basis. For example, as a program, Empower intentionally gathers diverse young people to work together. (This is contrary to the way that most HIV prevention programs function in urban centers, where funding is dispersed based on community-specific epidemiological data). While youth often talked about the sense of community forged across this difference, there were also losses. As Tumaini expressed, "Coming to Empower was definitely a loss of like, being with my own people. [...] People give and take a lot in order to participate in things. […] We don't necessarily show up because we have nothing to do."

Tumaini's photograph [figure 2] entitled "diaspora out of focus" and narrative expands on some of these tensions: *"*This photo is the fragmentation that is inevitable from being both other and away wherever I am, plus the space that surrounds it." While Tumaini concluded that there is creative possibility here ("our perspective pieces coming together to create an ever-refocusing whole moves away from the stagnant, monolith, one-size-fits-all model of programming"), the act of participating required ongoing emotional labour. As a racialized "diaspora babe living on this land" Tumaini writes: "[youth engagement] is a constant piecing together and refocusing."

Figure 2 - Diaspora Out of Focus

The labour and hidden costs of participating are rarely acknowledged or accommodated in youth-led programming. This puts an even heavier burden on young people, who must actively hustle to get their needs met. In figure 3, Lydia visualizes "a bike without a wheel" to represent youth engagement. She writes: "Locked - to a post. A mostly usable bike... a metaphor for ways we attempt to help youth, without actually considering the barriers they face or the support that they need." The photo is aptly titled "All you get."

Figure 3 - All you get

Perhaps not surprisingly, participants spoke evocatively, and sometimes with anger, about their struggle navigating programming that was supposed to be 'youth-led' but in practice, operated tokenistically, or without the proper supports. After reflecting on our group conversations, Chris expressed: "There's a lot of commonalities too, talking about burn out and experiencing barriers [or] difficulties in becoming engaged or remaining engaged."

"The exhaustion and the struggle:" Burn Out

During one of our workshops, I facilitated an icebreaker that asked young people to identify self-care strategies. I encouraged them to consider collective acts of self-care like creating shared communities or being involved in a project or social movement that advocated for social change. I created this activity in response to previous conversations about struggle and burn out. The icebreaker was meant to be warm-up exercise, however, it elicited so much conversation that it

took over an hour of our time. Participants insisted on the need to approach self-care structurally. In other words, they felt that a bubble bath is not enough if you are also battling intersecting systems of oppression (i.e., poverty, racism, transphobia, HIV related stigma). They wanted reprieve from their daily battles.

The impact of burn out, and its connection to larger structural issues, was evocatively expressed by Buttercup in her image "Seeds of Our Labour". [Figure 4] As she expressed in her narrative:

> As an advocate that is committed to raising awareness to issues that impact marginalized youth … I thought about some of the personal challenges. Like a rose that is so beautiful and vibrant in the beginning. As time progresses, without proper care and without being grounded, it wilts. The wilting resonates with my feelings of being burnt out; feelings of distress and agony that often comes along with doing this community work and challenging social norms. Ideally, we need sustainable supports so folks do not become burnt out and can continue to work progressively in HIV prevention, sexual health and harm reduction programs.

Figure 4 - Seeds of Our Labour

As Buttercup explained in our discussion, contending with structural inequities while often speaking on behalf of a community could be a burden:

> In terms of my own position as a trans woman, and also a woman of colour there are so many rich stories, rich narratives that aren't told […]. Sometimes I feel burnt out because I feel like a lot of pressure is on me, to deal with issues that have existed longer than I have. And also in terms of mentorship there are a lot of opportunities that got presented for me to be this role model to other youth but I sometimes feel burnt out.

Many youths tried to balance their exhaustion with opportunities to create change in their communities. However, they worried about whether their work was sustainable. This was illustrated visually in a photo taken by Michael, of a young man holding his grief alongside hope [figure 5]. As Michael expressed, "one day I'm gonna get tired, and then I'm gonna get exhausted, and who is going to be there to carry that work on?"

Figure 5 - #Hope

For Michael, this "battle" was fought alongside the grief and loss experienced in his community, and limited funding for youth-led work. As he continued, "Because of so many wars

and battle I've been through, I'm still trying to persevere, because there is still that sense of hope. ….. I'm not done yet but some days I do feel that with the stigma and all that, people hating on each other, that needs to stop."

This battle was also one of perseverance. He intentionally staged his photograph with the word "dream" in the background. In his photo narrative, he wrote:

> I am Salteaux First Nation and I made a photo called "hope". This photo is the sign of a person who was exhausted and saddened with the work he did in HIV prevention […] going to the further communities, northern communities, you see a lot of young youth that are struggling with water, with housing, and support systems, and neglect and denial. […] My only wish, as why I'm tired now as a 28 year old man, is that we find more funding support, less arguments over what organization works for what organization and collaborating together to go […] to those small reserve communities and go to those schools, and talk to the kids and tell them your story, that way they can have a sense of hope, and they can have a sense of light that they're not alone. That's my biggest concern and as an advocate, which is to help the people.

Others also remarked that this competition for scarce funds enhanced feelings of struggle. Issues of program sustainability, and the short-lived nature of youth-led program funding has been publicly addressed by others locally (Parris, 2018). At the time of the study, Empower was without stable funding (despite many funding proposals, and awards for 'innovation'). In this funding environment, not only could spaces of necessary support dry up, but lack of funding also introduced precarity for youth who were employed by programs.

Precarious funding environments and the battle for scarce resources created inequitable conditions for many, led to staff burn-out, and widened the gap between policy and practice. Two Bite Brownie provided an example:

> All the people that are dealing with the youth are burnt out because they want [youth] so they can get their results. The youth and the people that are teaching them on the front lines, and then there are the higher-ups there, they're not around […] they are just working with statistics and numbers and what sounds good and what looks good instead of what really is good and what's realistic and what can actually happen.

Here, "results" refers to statistics (i.e., numbers of people who participate). She continues: the program "may get some success [numbers] but the success they are getting, is only from people that have some certain amounts of privilege. […] while the other people that have no privilege won't be able to finish [the program] through no fault of their own." This illustrates that precarious funding not only threatens program sustainability, but drives program staff to push for higher numbers (to appeal to funders) which may privilege youth with access, and disadvantage young people who require structural supports. This also provides context for the following section on "specific types of participation" required by young people.

"Acting Engaged": Narrow understandings of participation

Participants shared that their participation in a program sometimes felt forced, or regulated to a specific type of 'active' participation. Participants told us there were many valid reasons why young people might not want to participate – temporarily or permanently. For example, Rainbow shared her story of first becoming involved with Empower, and the initial discomfort she felt around the subject matter (e.g., HIV, sexual health). She insisted that it was important that she still be able to be in the room, but not 'actively' participate. This enabled her to get more comfortable with the topic, and over time, she took on a strong leadership role. At other times, they noted that their desire to not participate – or participate in a way that felt good for them – was not acknowledged or taken seriously. As Michelle explained, "It's like when youth are not the ones creating these spaces … To what end are we saying that they must participate in this very specific way?" For example, in some youth spaces, participants were expected to disclose personal information, share feelings or oppinions, or participate in an activity when they were not comfortable, or when they were tired or stressed from having to navigate other challenges in their lives.

For example, Kamilah visualized youth engagement as a set of interconnected polls, shot from the "ground up" [Figure 6]. She explained that the polls represented "being connected to one another…this reminded me of community […] and that when we are connected to one another we can mobilize in ways that we might not be able to on our own." At the same time, she explained "Where I am right now in life has changed my feelings towards how I feel about youth engagement." She likened this feeling of exhaustion through the metaphor of a train

Figure 6 - Untitled.

> just about to come in to the station - I feel like I am always just barely catching things, moving by the seat of my pants. I'm just kind of looking at this space and trying to figure out where I belong and how to move through all these pillars, polls, how to climb the ropes in between them. It's complicated. Even when the resources are around.

This constant feeling of exhaustion could prove particularly complex when there were expectations that one participate in a particular way to access resources (e.g., to receive honorarium). This prescriptive script often set-up a false dichotomy where one had to 'choose' between their self-autonomy (i.e., follow their desire to *not* to participate) or access community support or resources. As Tumaini explained: "I think if people are forced like, 'oh if you do not participate in x way, you cannot be in this room' …. you aren't going to have access to this information and like, support and community." On the other hand, participants told us that they might be made to feel deviant if they did not participate as expected. Two Bite Brownie shared:

"Sometimes the facilitator thinks they know best …. If the program isn't working for you, they say it's your fault …[you] think you're not good enough." She explained that sometimes she felt she had to put on a façade or "act fake" in order to "get by."

The expectation of "specific types of participation" can have serious consequences on young people's well-being, especially if young people are asked to actively participate in activities that might bring up difficult emotions, or discuss sensitive issues (e.g., drug use, sex work, experiences of trauma). For example, Two-Bite Brownie told us that in some program spaces, she is not allowed to go on her cell-phone, despite voicing that she needs it to cope with anxiety. As she argued, "I am doing what I need to participate, so that I can participate more meaningfully later, and in a good way." Alternatively, Keeky told us about negative experiences she had while (voluntarily) attending a local youth drop-in for two-spirit, lesbian, gay, queer, bi, and trans youth:

> There are many reasons …why some people may not be comfortable doing certain activities, and I know how it was like when I first went to [youth-drop in organization] in 2010 … I knew how much it really hurt me that [the staff] would often force me to do things I did not want to do. Like, I think he was like that with me because of the fact I was a youth and the fact that he knows I'm differently-abled and have mental health problems.

Over time, this led Keeky to stop attending the program. Both Two Bite Brownie's and Keeky's experiences signaled that in many programs, young people may not have their decisions to 'not participate' respected. As Keeky articulated, this patronizing view must also be considered intersectionally – in this case, alongside age and ability. This is bolstered by ageist and ablest understandings of youth as 'pre-adults,' unable to make agentic decisions (Tuck & Yang, 2011). Young people, in particular young people with disabilities who have other intersecting identities, are often positioned as without bodily and self-autonomy (McClelland et al., 2012). While the specific activity Keeky is referring to is unknown, her words can be read in-line with a larger history of mandatory schooling, youth employment programs, juvenile detention programs, case

management or counselling initiatives designed to regulate young people's bodies, especially if they are poor, racialized, disabled, indigenous and/or queer. Many asserted that organizational staff, clinicians, and other practitioners must see them as complex, human-beings with active desires, knowledge, and agency to make informed decisions about the contours of their involvement. As Michael powerfully explained, "I am human too."

"Let her Be": Accessibility, Trust and Self-Determination

As described above, young people articulated the material and discursive effects that the 'call to participation' had on their lives and bodies. And yet, as explored elsewhere (Switzer et al., 2016), many Empower youth also believed fervently in the potential of youth-led, participatory spaces, and the role they could play in connection with larger social movements. In this light, non-participation had generative possibilities, if seen through a lens of self-determination. As Lydia expressed with her photograph and narrative, *Growth* [figure 7]:

> Seeds drop into an empty pot.
> Left and forgotten. Dry and cold.
> Panicking while being transported.
> Temperatures changing and severe.
> Mist of water, warm light, and the cold window pane.
> Wait...
> Sprout. Quickly growing, when left in peace.
> Given food and light.
> Respectfully left on its own.
> And given time to settle.
> To grow at its own pace.

Figure 7 - Growth

Here, growth came from being "left in peace." As Buttercup echoed: "Sometimes people need to be left alone to really determine things for themselves and develop an understanding of what their needs are before being around other folks, so like that's a way of supporting a person, by giving them some space. Fall back." The last two words of this quote act as a call to educators, youth workers, and researchers to take important cues from the young people they work with, to let them lead the way, and set their own agendas for involvement.

As Buttercup shared, "People are struggling with like a lot of things and life things, and communication can be hard. So, there needs to be flexibility for programming in terms of the time, in terms of the day and still create the alternative support for youth who want to be engaged even if it's just temporarily." Participation 'levels' and forms may shift over a workshop, or project. For many participants, deciding when to participate and when not to was not always a fixed process. In other words, the "zone" between being involved or not did not have to be a binary, provided it was rooted in an ethics of self-determination.

In one of our conversations, I asked if the group thought the 'right to pass' was important - a phrase frequently invoked at Empower when you did not want to participate in a check-in/out, or a sharing circle. Lydia responded by speaking to the importance of trust-building: "We've worked with each other for years, and we all know each other, which is why we feel comfortable with each other talking about these things, and … giving whatever participation we're able to give." Later, when we met to discuss this article, participants responded to initial findings with comments about hope, chosen family, and relationships forged over time. Some of us have known each other for years. Participants insisted that one needed trust, compassion and understanding to negotiate many of the issues addressed throughout. As Michael shared, referring to a time when someone needed to take a break "let her be – she's still family." He waved his arm, and signalled to us at the table: "if I need a cigarette break, *you'll* understand."

This focus on relationships and trust suggests that the topic of non-participation may only become intelligible when young people feel safe enough to voice it. Otherwise, young people may just disappear (i.e., actively choose not to participate) from a space all together. Nonetheless, as many Empower participants (those in the study and others) have taught me over the years, while relationship-building is a long-term process, one must work to build trust in the short term – one conversation, mistake, and encounter at a time.

Discussion

In our study, young people spoke to a range of dimensions of non-participation that practitioners, educators, and participatory researchers may want to consider when designing or leading programs. The following section explores young peoples' narratives of non-participation in relationship to critical scholarship on neoliberalism, settler-colonialism, and the 'will to participate.' Putting these different voices in conversation with one another helps to interrogate

often taken-for-granted assumptions about participation, and youth engagement as dispelled through common linear participation typologies. It also illustrates the extent to which participants were aware of how the 'call to participation' functioned in their lives.

Youth, willing participation, and the neoliberal, settler-colonial order

While participants did not speak directly of neoliberalism (as a concept), by identifying the discursive and material effects of the 'call to participation' (burn out, hidden costs, and 'specific types of participation required'), youth actively deconstructed ideas of the rational, neoliberal actor who is able to simply show up and participate. As Kwon (2013) argues, to become a good citizen-subject necessitates *voluntarily* and *willingly* participating in youth programs or organizing efforts. In other words, subjects must do more than simply obey, they must do so of their own free will (Ahmed, 2014). Participants' insistence that they must "act engaged" in order to access services/programs calls into question concepts of voluntary and 'empowered' forms of participation that predominate many conversations about youth engagement.

Ahmed (2014) explains that a subject may also will in particular ways when the consequences of force are too much to bare. Here, one might apply will to participation. As Ahmed explains, "thinking through will is an invitation to think through force differently. Force can take the following form: *the making unbearable of the consequences of not willing what someone wills you to will*. […] Willing is not only a way of avoiding the consequences of being forced but also of coming off less badly given the force" (p. 55-56, italics original). In other words, one must "act engaged" to not experience the consequences of being forced. As Keeky narrated, the expectation of participation can be something akin to force.

A subject can also consider their own self as willfull (one who turns or vies against the self) when they are not able to bring about a desired action within their self (Ahmed, 2014). How

might this apply to burn out, and young peoples' daily struggles to get by in the face of mounting structural challenges? Or, to not being able to participate in the way they feel they 'ought' to? In one of our workshops, Two Bite Brownie broke into in tears when talking about her struggle to 'keep up' and actively participate in a youth employment program that expected her to participate without proper supports. She felt that the program was designed for young people with class privilege - who lived with their parents, rather than youth living in poverty. After asking for her needs to be met (e.g., honorarium payment on time, transit support) and having them denied, she felt that she had become a "problem" for the organization that she explained often touted an equity-lens. As Ahmed explains, being willfull is not just disobeying, or not willing in the right way. Instead, "[w]hen willfullness sticks, you become the trouble you cause" (Ahmed, 2014, p. 90). Or, as Guta et al. (2013) argues, the neoliberal logic of voluntary participation "inevitably benefits some more than others. Those individuals who are *unwilling* or unable to benefit [from participatory programs] then become marked as underserving, unworthy and even dangerous" (p. 435, italics mine).

The neoliberal logic of participation has particular implications when thinking about certain communities, in particular Black and Indigenous youth, and/or queer and trans youth living in poverty who already have their lives surveilled and targeted by the state (Cruz, 2013; Kwon, 2013; Maynard, 2017). Some youth – often falling intersectionally on the axes of gender, race, sexuality, class, indigeneity, HIV status, drug use experience, and ability - are more likely to be charged with being willful or, deviant. In her text *Uncivil youth: race, activism, and affirmative governmentality* Kwon (2013) explains:

> In the current era of neoliberalism, the will to empower and be empowered is exercised as a mode of power intended to regulate and enable young people by encouraging them to participate in non-profit programs meant to protect them from the risks of their environments and also from the threat of becoming 'at risk' (p.56).

As Kwon (2013) explains, this rhetoric is particularly prominent in capacity-building programs targeting youth of colour, including those operating from a social justice mandate. This rhetoric may also apply to community-based participatory research projects designed to alleviate social injustice, and provide employment opportunities for those living on the margins. Guta et al. (2013) explains that when applied to peer researchers, this logic can work to govern subjects by shaping or re-directing individuals into more productive citizen subjects, especially through appeals to increased social functioning, self-improvement and productivity.

Neoliberal logics of participation also work in tandem with settler colonialism. As referenced above, settler-colonialism functions by reproducing "forms of life that make settler-colonialism's constitutive hierarchies seem natural" (Coulthard, 2014, p. 152). Functioning through the practice of concealment, these constitutive hierarchies are embedded in our health, research and educational institutions (Veracini, 2010). Thus, one might ask – what does the teleological 'call to participation' *do?* What does it enable, and what does it conceal?

Dhillon (2017) sketches how the logics of participation have been used as a guise for continued settler-colonial rule, when employed by policy makers, social workers, researchers, and educators working with Indigenous youth. She has argued that the "logics of participation" function:

> as a mechanism to recalibrate relations between the governing and the governed. This reconstruction, however, takes place within a context of settler colonialism that simultaneously distances the political and legal entity of Canada from its history of conquest while purposefully fostering a new national imaginary of the peaceful postcolonial (p. 21).

This "peaceful postcolonial" is one where young people are equipped with low-skilled jobs, and positions within participatory programs, but Northern reserves still do not have access to clean drinking water, or land sovereignty. As Dhillon (2017) argues, "participation does not exist in a neutral, suspended space, empty of power and history, nor are its benefits necessarily axiomatic or

its implications readily predictable" (p. 14). Ocean (Giiwednangoonhs Kwe), another Empower youth, similarly critiqued youth employment programs for their individualistic-approach to capacity-building: "How am I supposed to give back to my community when all I've obtained is painting skills? Up and down, you know?" (Switzer et al., 2016, p. 122).

Dhillon's words strike a strong chord with those of participants, who continually echoed that in many participatory projects, it was not just whether you participated but *how* you participated that mattered. Participants were also aware that this call for participation existed beyond themselves, and the agency. Under a neoliberal and settler-colonial frame, the state also gains access to one more figure who governs through participation: the underpaid non-profit employee (Kwon, 2013). Many of the young people in Empower had transitioned into roles of youth workers themselves, and were well aware of this paradox.

Non-Participation as Refusal

Given the above critiques, how might we follow the lead of Empower participants to think through the productive possibilities of non-participation? How might we re-conceptualize our projects or participation frameworks so that we envision young people as capable of navigating participation on their own terms? Or of saying no, not today, but maybe tomorrow? Or no, not under these conditions, but perhaps others? How might we see young people who claim a position of non-participation, not as deviant, but as agentic individuals who come to projects with an understanding of calculated risks? Milne (2012) critiques literature on participatory [video] projects for narrowly focusing on issues of trust or participant recruitment when participation levels drop. She argues that non-participation should be understood as something a participant might actively chose at any stage. While she does not disregard structural project factors, she

argues that simplistic accounts of participation fail to engage with the many reasons young people withdraw from projects, and can actually strip participants of their agency by painting them as lazy, or having overwhelming, and chaotic lives. As evidenced above, young people spoke in very clear terms about the function and effect of participation. They know that participation – even when desired – often involves giving something up. They are not naive.

What would it mean if we saw non-participation as an active choice, calculated act, and even, an act of resistance? Take for example, strategies of political refusal employed by the Mohawk nation as described by Kahnawake Mohawk scholar, Simpson (2014). By describing many of the ways the people of Mohawk nation actively dis-engage with the state (the refusal of the 'gifts' of the state founded on ideas of tolerance, recognition, etc.), she prompts us to deconstruct liberal and multicultural ideas of equal footing that community engagement strategies are often premised upon, and to think about the potential of refusal as a political strategy. Simpson asks: "What happens when we refuse what all (presumably) 'sensible' people perceive as good things? What does this refusal do to politics, to sense, to reason?" (p. 1). Or, in this context, what does this refusal do politically, and conceptually, to our participatory projects? What does it turn on its' head?

In the context of many community engagement projects (led by government, or non-profit organizations) that invite specific forms of public participation, the decision *not* to participate may be an active strategy of resistance for young people, especially those whose lives have been highly administrated by the state. As many critical youth scholars point out, youth actively resist domination in many ways (Cammarota & Fine, 2008; Tuck & Yang, 2011; Tuck & Yang, 2014b), albeit in modes we might not expect (Tuck & Yang, 2011). Drawing on Lugones' (2003) work of resistance in "tight spaces", Cruz (2011) shares how many of the strategies of resistance that

2SLGTBQ youth who live on the margins employ are not intelligible within public resistance tropes. These are "hidden transcripts" of resistance (Scott, 1990). She argues that for young people whose bodies have been surveilled, or viewed as 'at risk' by organizations, and their workers, resistance must not be viewed as an individual, defiant act, but rather, one that is linked with larger collective actions and histories. For example, Cruz (2013) shares a story of trans youth who stop attending a drop-in. They do so to subtly resist the centre's decision to hire security personnel that do not affirm their gender identities. Many trans, two-spirit and gender-non-conforming young people at Empower have shared familiar stories.

We might also consider participants' involvement in this study as part of this frame. Under the logic of participation (and within a project on participating and engagement), what does it mean for young people to participate by taking photos that speak not to the benefits, but the costs of participating? For many youth, creating cultural forms of production that refuse expected ways of being may be an active act of (political) participation in and of itself (Gaztambide-Fernández & Arráiz Matute, 2015), especially when young people's public participation is constrained by colonial contexts (See: Desai (2015))[3] During the study, many participants shared contradictory experiences with me on and off-tape. I had long-standing relationships with many of the participants and knew larger pieces of their life-stories. I saw these acts of departure as evidence of their research savvy, and their ability to distinguish between their relationship with me, and their relationship to research, owned by an institution. It was their act of refusal. These forms of resistance are often marked by the stories youth "tell you on their own terms," and are found somewhere in the "zone of constant struggle" between hidden and public transcripts (Cruz, 2013,

[3] Desai (2015) explores how the work of Palestinian youth film-makers may be seen as a politics of refusal when "shooting back" (film-making) in the occupied territories.

p. 7). They are also acts of not participating that bear a striking resemblance to many of the narratives expressed throughout.

Implications: Non-Participation and New Imaginaries

Participation rarely resembles forms evoked by dominant typologies. We do not get on at point A and get off at point Z. Our conversations intervened in romanticized, linear narrative of 'un-engaged' to 'engaged' that are depicted by many youth engagement frameworks, where non-participation is positioned negatively on the bottom of Hart's often-cited ladder. Returning to the work of Tuck (2013): what if we thought of change, not as a linear progression, but in the way that we balance a baby on our hips, as we shift the weight from one hip to the next? How different would our projects look if we took up this conceptual shift in thinking about what it means to move through a participatory process? If we centered non-participation not as a missing, or bottom step, but an integral and productive part of our work with young people? Who else, and what other kinds of thought or subject positions might it call into our projects and lives?

Young people's experiences bring the critical scholarship raised in this discussion home. Together, their voices ask us to pointedly question: who actually benefits from participatory processes, especially those steeped in larger institutions? When do participatory aims serve detrimental ends? When is participation not a choice? And, when is it? As a participatory researcher, and former front-line worker with longstanding relationships with many of these young people, their words sit with me, tug at my shirt, and root themselves in my belly. When we met to discuss this paper, Michael asked me: "how long has it been Sarah, how many years?" Their words on non-participation are the cherry pit I swallowed that later sprouted. I am both grateful for their offerings, and anxious that I have enacted the critiques they lodge. I likely have. I have drunk the participation kool-aid, and yet I am humbled that they trusted me with their refusals.

There are a few limitations to this study. Empower consists of a relatively small group of youth who have worked together for many years in different configurations. While this created a sense of trust, I was consulting with young people who had already accepted the invitation to participate. I was *not* discussing participation with those individuals who never entered the organization's door. This conversation may have been very different had I consulted with young people not already involved as leaders in youth-led programming. Furthermore, the participatory nature of the project likely privileged young people who were more likely to participate. Nonetheless, as evidenced above, this did not restrict them from speaking powerfully, and eloquently to non-participation – in and outside Empower.

For those of us committed to participatory processes with young people, participants' words ask us to consider the material and discursive possibilities that the lens of *non-participation* engenders. As Walter and Hyde (2012) note, "[h]ow we conceptualize community powerfully influences what we see and what we do in community practice" (p. 78). There are many ways to build opportunities for non-participation into programs as explored throughout, as well as elsewhere (Switzer et al., 2017; Switzer et al., 2016) – provided self-determination is at the forefront. Sometimes, in the context of mental health issues, structural challenges, and loss, not participating can be the rational choice. Sometimes, not participating as Lydia's photo [figure 7] identified, can be a pathway to growth, or to Hope [figure 5] -- if only we listen.

Conclusion

Choosing not to participate (either temporarily or permanently) may have generative possibilities. In our project, 11 young people at Empower, a youth-led HIV prevention and harm reduction program were asked to take photographs to visualize how they conceptualized engagement. In response, participants told us about the hidden costs of participating (including

burn out), what it meant to "act engaged", and the importance of trust and self-determination. They had sophisticated understandings of how the 'call to participation' functions both materially and discursively in participatory projects. In this article, I explored these articulations under what I (and others) call non-participation – the active choice to not participate. Considered in the context of scholarship on neoliberalism, settler-colonialism, and will, these accounts demonstrate that young people are quite savvy and aware of how participation functions. In this context, non-participation may be considered a form of refusal. Practitioners would be wise to consider the possibilities that non-participation engenders.

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Conflict of Interest[1]

I am told I am not supposed to have previous relationships with my research participants. I am unsure who comes up with these guidelines, or who composes them. This is not to say boundaries are not important. But they are sometimes messy, complicated, composed somewhere between a reception desk and the act of disclosure, a hug in the hallway 4 years later, when I thought you might be gone. A phone call on Friday at 9:00pm, unexpected:

I'm in the hospital - please come. I don't know what to do.

Composed somewhere between
a clutched stone and a pocket poem
partially written: what you see
what you don't see.

A nod to past gatherings –
round spheres spinning outwards
over time: a silent story-telling circle
where no one wants
to tell their story, a check-in, and
here they are, here
we are, 6 years later, brilliant,
and I am so proud I could
cry but research ethics
tells me I'm supposed to be impartial
so I hold my tongue, and
mix my words
instead.

[1] Maintaining roles and boundaries is an important element in CBPR, and in this dissertation. I had known some of my participants in various professional contexts for many years. While I was not new to some of the complexities of boundary work, there were many challenging moments during this project, where different 'roles' collided with one another.

Chapter Five[2]

Working with photo-installations and metaphor: New directions for photovoice research

"I wish, instead of looking for a message when we read a story, we could think, 'Here's a door opening on a new world: what will I find there?'"
– Ursula K. Le Guin, 2009, p. 129

Introduction

The use of participatory visual methods (PVM) in applied research has proliferated, opening new ways of seeing and thinking about research (Cox & Lafreniere, 2010; Pauwels, 2015). The move towards PVM can be attributed to the 'participatory' turn in the social sciences, in response to feminist, post-colonial and postmodern critiques about positivist conceptions of objectivity (Gubrium & Harper, 2013; Packard, 2008), and the increased interest in health and education for moving research findings beyond academic audiences (Fraser & al Sayah, 2011). As these methods gain popularity, there can be a disparity between the way PVM are theorized, imagined, and facilitated. To achieve greater alignment between aspiration and practice, it may be important to return to fundamental questions about the purpose and role of images in PVM.

Photovoice, as initially developed by Wang and Burris (1997), offers participants cameras to identify, document, and analyze issues in their lives with the aim of creating program or policy change. Photovoice draws upon the following traditions: 1) Freirean ideas of dialogue, agency, and critical consciousness; 2) feminist theories of reflexivity and the co-constructed nature of research; and 3) documentary photography; visual sociology and anthropology; and/or arts-based research – in different variations (Gubrium & Harper, 2013; Latz, 2017; Liebenberg, 2018).

[2] This manuscript will be submitted to a qualitative research methods journal. It is sole-authored.

Despite these theoretical roots, many proponents of photovoice operate with a realist approach to the image. In this tradition, the image is understood as an evidentiary artifact, or a transparent entry-point to participants' viewpoints, experiences, or understandings. This realist or "docu-photo" approach can obscure the co-constructed nature of the photovoice process (Gubrium & Harper, 2013). This has several consequences. A realist approach to photovoice disregards prolific work by scholars who speak to the 'truth effect' of photography (Tagg, 1999; Wells, 2003), or its social and/or technological history (Benjamin, 1972).[3] As a technology, photography is not neutral. It has a long history of constructing racial discourse (González, 2006). When working with communities who experience marginalization, this 'truth effect' can inadvertently 'fix' communities in particular ways, especially when images travel outside research contexts. This has implications for employing PVM when working with communities who are already surveilled by the state, such as young people of colour, or people who use drugs (Switzer, 2018). Prominent visual scholars consider images to be crafted representations, where meaning(s) emerge in the relationship between image, viewer, producer, and the larger world (Evans & Hall, 1999; Pink, 2013; Rose, 2012).

Reflexivity is a central element of photovoice methodology. A researcher's own lens will always impact the production and reading of images (Mitchell, 2011). Orientations to photography will influence study design, and the types of images or aesthetic strategies that are intentionally (or unintentionally) promoted within a project (Brushwood Rose & Granger, 2013; Latz, 2017).[4] Additionally, fixing the meaning of an image eschews the benefits of working with the visual. If

[3] This tension is not unique to photovoice. The debate between the function of photography (i.e., realist or creative) has been in circulation since the turn of the late 19th century, and is often linked to discipline (e.g., health, law, and medicine, vs. art, semiotics, advertising) (Benjamin, 1972; Wells, 2003).

[4] We must also consider how our subject locations (e.g., gender, race, ability, sexual orientation) and life experiences shape our ways of looking and thinking (Moosa-Mitha, 2005).

framed appropriately, images can introduce multiple entrances, readings, and perspectives into our understanding of an issue, thereby expanding opportunities for the uptake of research (Capous-Desyllas & Morgaine, 2018; Weber, 2008). As Brushwood Rose and Low (2014) argue, taking up PVM as "crafted as well as empirical, acknowledges that [methods] emerge, not as direct or transparent reflections of experience, but as products of a creative and often imaginative process, which involves acts of invention, aesthetic choices and a significant amount of editing" (p.38). Although photovoice will not create program or policy change in and by itself (Liebenberg, 2018), if the goal of our projects is to create social change, PVM researchers may want to explore methodological approaches that *open up* meaning, rather than foreclose it.

In response to these tensions, in this article I explore the crafted role of image-making in the context of a photovoice project that asks stakeholders to visualize engagement in the local HIV sector. Although "audiencing" (Rose, 2012) has been addressed in visual studies for decades, photovoice exhibitions - and the pedagogy of these exhibitions - is an understudied area (Mitchell, 2015). Furthermore, although the facilitated nature of PVM is generally understood, researchers seldom write about the pedagogical nature of their projects.

In the *Picturing Participation* project, participants created and exhibited 67 photographs and narratives that relied heavily on metaphor as a crafted strategy. Metaphor applies one object, thought, or action that is known to another, unlikely object. In contrast to positivist ideas of expressing data, metaphor is less about representing tangible, concrete facts, and more about communicating an essence, or feeling that is often outside of language (McIntosh, 2010). They also created 3 site-specific photo-installations. Installation art has several properties. Installations are made for specific spaces, explore characteristics or qualities of this space, and involve every-day objects in sometimes unusual ways to encourage audience interaction from multiple

viewpoints (González, 2004). Installations also often work with metaphor, or an economy of symbols.

Although metaphor is a common aesthetic trope in PVM (Lorenz, 2010; Mizock, Russinova, & Shani, 2014), the crafted-nature of visuals is rarely explored in detail in visual methods literature (Brushwood Rose & Low, 2014). Drawing on field notes, participant-produced photographs, and installations, I reflect on my pedagogical orientations to the project in order to highlight the process by which we arrived at our final, *crafted* exhibit. In doing so, I illustrate how certain design elements created the necessary conditions for participants to visualize their ideas through metaphor and installation. In contrast to a docu-photo approach, I ague that participants' reliance on metaphor, and our co-produced installations created new possibilities for synthesis, dialogue, and dissemination. I conclude with a theoretical discussion of the possibilities for taking a crafted, and reflexive approach to image-making in photovoice studies.

Methods

Study Design

Picturing Participation: Exploring Engagement in HIV programming, service provision, and care is a community-based participatory research (CBPR) project that used photovoice (Wang & Burris, 1997) to explore how different stakeholders understood 'engagement'. CBPR is an approach to research in which stakeholders co-lead all stages of the research, from design to data collection, analysis, and dissemination (Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2008). A team of academic researchers, community members and service providers partnered with three community-based sites to do this work. The sites included: Empower, a youth-led HIV prevention and harm reduction program; Casey House, a sub-acute HIV hospital; and

Toronto People with AIDS Foundation (PWA), an AIDS Service Organization. Each site represented a different organizational context within the HIV sector. Study participants included program participants, clients, peer volunteers and staff members in various roles (peer workers, coordinators, clinicians, etc.). The project adopted a comparative case study design (Yin, 2003).

The overall study design is represented by figure 1. The project resulted in a number of outputs, including a community exhibit and report launch, where 63 photographs and 3 installations were shared with approximately 100 attendees, including community members, service providers, and policy makers. I led and nested my doctoral dissertation within this project, and had previous relationships with each of the sites.

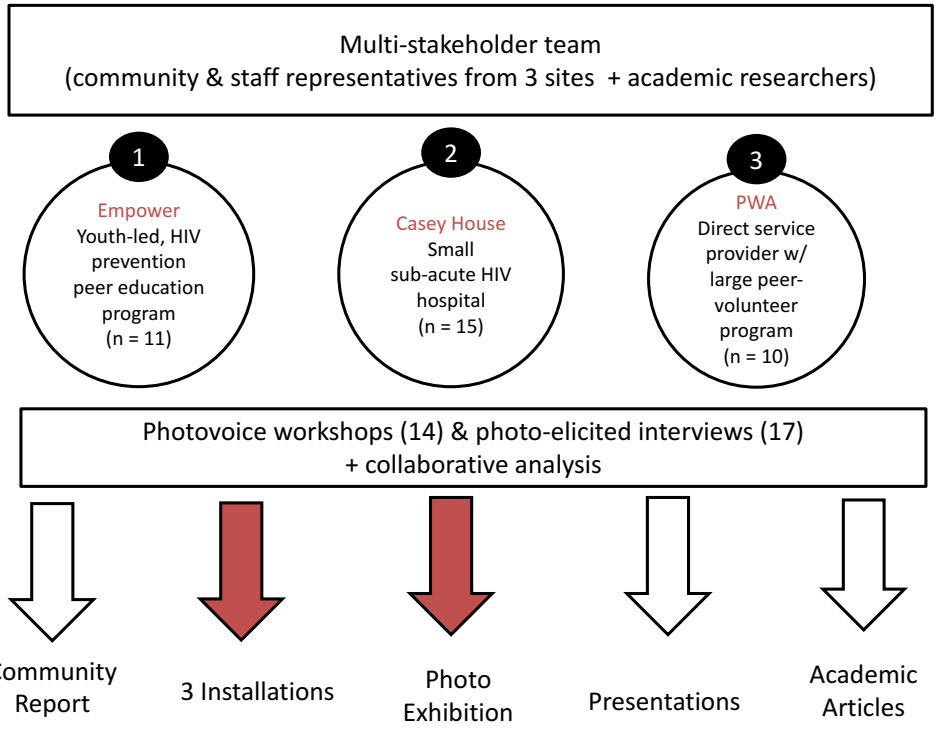

Figure 1 – Project Overview

Theoretical Orientations

Despite attention to researcher reflexivity in visual research, photovoice scholars seldom report on the theoretical lens they bring to their projects (Liebenberg, 2018). Although the project was designed with a CBPR approach, I arrived with my own theoretical ideas about engagement, based on over thirteen years of coordinating peer-led, arts-based projects within the HIV, sexual health and harm reduction sectors, and a deep immersion in the literature. My theoretical imprints can be found across the study. This is not an anomaly. What is atypical, however, is my desire to draw attention to these markings (following the work of Lather (1986)) in an effort to trace their impacts.

I was particularly invested in challenging the idea of engagement as either an end or an instrumental means. Rather, I understood engagement as an affective, dynamic and pedagogical process, deeply invested in what Ahmed (2014) describes as the "not yet." I considered engagement, as the etymology suggests, as a commitment to showing up to a process that is fundamentally unfinished, with its potential transformation (if we can even call it that) lying in collective dialogue, grappling, and imagination. For me, engagement was not an end (a community was engaged) or means (we engaged a community in order to), but a *beyond*. Each of the sites also challenged me to think about engagement differently. I wanted to invite participants to bring their own understandings, and to collectively co-theorize about engagement. Inspired by Tuck et al. (2008), Sánchez (2009), and Herising (2005), I wanted to challenge the idea that there is a firm boundary between the one that theorizes (i.e., the researcher), and the one that is theorized about (i.e, the participant or 'subject').

Photovoice's focus on the strengths of a community, ongoing group dialogue, and its collaboratively-led program and policy change focus, made it an appealing fit for co-theorizing

(Aldridge, 2014). Engagement is a 'fuzzy' concept (Head, 2007), and the act of taking and talking about pictures could help participants make their understandings concrete, by acting as a site for individuals to reflect on their everyday experiences and understandings (Mannay, 2010). My prior experience working with PVM had also encouraged me to think about how I might challenge the 'truth effect' of photography, embrace participants' visual literacies, and think more intentionally about representation (Switzer, 2018). I wanted to re-fashion photovoice as a site for dialogue and co-inquiry rather than an entry-point into viewing some fixed, local reality. Encouraging participants to see their visuals as crafted representations was one way to achieve this, and adjoined with my interest in co-theorizing. As a poet and an amateur photographer, I was also not a stranger to working within an economy of signs and symbols. Prior to the study, I had participated in a workshop in which I learned to physically manipulate printed photographs, which likely influenced my openness to working outside traditional photographic formats.

Conducting doctoral work while also trying to 'co-theorize' comes with unique tensions (see also: Sánchez, 2009). To attend to this, I opened up the planning of photovoice workshops for greater influence, and contribution by team members. Participants also made decisions about analysis as explored elsewhere (see: Community Report and *Journeying Together*). Moving forward, the 'we' in this article signals and honours this collective effort.

CBPR meets photovoice: Workshop design and approach

Over a period of six months, 20 photovoice workshops and 17 photo-elicited interviews were conducted with participants across the 3 sites (figure 1). Workshops were facilitated by myself and Kamilah Apong, a community-based research assistant and former Empower coordinator, and

supported by student research assistants. As will be discussed below, many team members supported workshops behind the scenes, including representatives from each site.

Unlike a docu-photo approach, we approached image-making in photovoice as a way to open dialogue and invite different ways of thinking about engagement. Community-representatives also requested that we provide opportunities for participants to be creative. Photovoice as initially developed, follows a prescribed method of issue identification, photo training and instruction (including ethics), discussion, and analysis (Wang & Burris, 1997). It usually occurs over several weeks, and in group format. However, because workshops are highly facilitated, they are usually designed in advance by researchers. Thus, using the photovoice process as defined, is sometimes at odds with the participatory, co-development nature of CBPR (Catalani & Minkler, 2010; Nykiforuk, Vallianatos, & Nieuwendyk, 2011). While there is a general acceptance that photovoice will need to be modified to the study context, those writing about the co-design and development of photovoice projects (in a CBPR tradition) is limited (Castleden, Garvin, & Huu-ay-aht First Nation, 2008). In this project, I conducted multiple conversations with team members before, during, and after the design and implementation phase. How we facilitated the workshops - including overall design, the development of photo prompts, and creative icebreakers - was reviewed by our co-investigator team, including community representatives from each site.

In our study, at each site we introduced the project, brainstormed ideas about engagement, provided training on ethics and photography, and discussed, analyzed, and celebrated participants' photographs (figure 2). Based on discussion with team members, the format of the workshops at each site differed slightly to take into account ethical issues and participant needs. Our participants had a wide range of accessibility needs; it was important that we design our workshops to reduce as many barriers as possible. For example, each workshop included icebreakers that were adapted

to the needs of each site. Participants were quite diverse with respect to their identification in terms of race and ethnicity, Indigeneity, gender and gender identity, HIV status, drug use experience, housing, and immigration status. Some participants also struggled with mental and physical health challenges. The following section details our workshop design, and the ways in which design elements may have impacted participants' interest in metaphor, and later installation.

Figure 2 – Photovoice Workshops

Project Orientation and Brainstorming

Our first workshop introduced participants to each other (and us), and oriented them to the project. Since the concept of engagement can be abstract, prior to asking participants to take and talk about their photographs, we led participants through a series of creative activities in order to center, and draw out pre-existing ideas about engagement. Given my relational understanding of engagement (as described above), it was also important that we discuss these ideas together. For our icebreaker, we arranged miscellaneous objects on a table (figure 2). Participants were asked to select one object that represented their ideas about engagement and to share their thoughts.

Working with objects encouraged participants to consider multiple ways of thinking about engagement (i.e., participants heard a range of ideas and understandings), introduced participants to the concept of abstract or symbolic thinking, and encouraged them to share broad understandings of the concept.

Guiding principles for the activity ("there's no way to do this wrong" and "don't over think it") encouraged a non-rational, or creative approach. Participants' responses were worked into our photo prompts (see workshop 3). Although not initially planned, this opening object activity set the stage for later photos participants would produce and their eventual turn to installation. The icebreaker was designed to support participants in feeling comfortable with us and each other. It also supported the discussion of engagement, by making our conversations more concrete, without relying on a docu-photo approach.

Photographic and Visual Ethics Training

In the second workshop, we introduced the idea of photographic composition and encouraged participants to try out their photographic skills prior to taking project-related photos. Participants were trained to use point-and-shoot digital cameras that they could keep following the study. Most photovoice studies include a brief orientation to photography including ethical photo-taking guidelines (Catalani & Minkler, 2010), but it is rare to find studies that document training in composition (Sandlin, Szkupinski Quiroga, & Hammerand, 2018). While not all photovoice researchers agree with including composition as part of this training (as they see it in opposition to a realist approach), many of our participants expressed an interest in learning more about photography as an art medium and the focus on photography as craft was a draw to our study. It is also my experience that participants come to photovoice projects with a range of visual literacies that they are interested and willing to share with others (Holtby, Klein, Cook, & Travers, 2015;

Switzer, 2018). Hence, it was important to support participants in developing their own visual vocabularies by foregrounding and expanding on the visual literacies participants already brought into the project. At all sites, people's experience with photography varied, and many enjoyed sharing their photographic strategies with others.

For our composition training, I brought in a selection of photographs (some taken by me but most cut out from commercial and art magazines) that reflected a range of visual strategies (figure 2). Participants were asked to select one image that interested them and describe one visual element that they liked about the photo (e.g., perspective, framing, light, a photo that tells a story). Contributions were recorded on a flip chart. We concluded the training with a brief presentation on considerations for taking photos including ethics. However, by the time we arrived at this stage, at all sites, nearly all the presentation points had been addressed by project participants (and more). The presentation thus served to cement the idea that participants *already* had the tools – and now the language – to take compelling photographs. As a group, we discussed that there was no 'one way' to make a 'good' photo.[5] I stressed that since everyone was able to identify one visual element during the exercise, they already had the collective knowledge to craft their images.

Following this, participants took part in a photo-scavenger hunt, that site-representatives and I designed to encourage participants to trial different ways of taking photos, including some of the visual and ethical strategies they identified in the workshop (e.g., take a photo from an interesting perspective, show a creative way of keeping yourself anonymous). During this workshop, many participants spoke about the role of photography in telling a story through narrative and metaphor. They expressed strong interest in photographs that had an affective impact on them and expressed excitement about their new skills, and the task at hand.

[5] It was important to disrupt hierarchical understandings of quality or 'goodness'. As Tavin (2007) argues, drawing on the work of Bourdieu, the concept of aesthetic goodness is historically loaded.

As homework, participants were encouraged to practice taking photographs, and take one photo that represented what engagement meant to them so that we could troubleshoot any issues at the subsequent workshop.

Photographing Engagement

In the third workshop, we provided participants with clear and specific instructions for taking photos about engagement. Many of our participants had learning disabilities, cognitive challenges (e.g., brain injuries), and physical health needs, so accessibility was important. We began by brainstorming ideas about engagement on a flip-chart and shared our own understandings, where appropriate. We also shared some of the engagement-related photos participants took as homework, and troubleshooted issues as a group (e.g., how to deal with shaky hands, ask for support, or how to think about an issue or idea visually).

Facilitators, and the prompts they provide, can influence the photographs that participants choose to take in any PVM project (Gubrium, Hill, & Flicker, 2013; Luttrell, Restler, & Fontaine, 2012). Our instructions were developed collaboratively with the support of research team members (including site-representatives). Each participant received a handout with instructions. We asked participants to reflect on what "engagement" meant to them personally, what it looked like in practice at their site, and to take photos that represented their ideas. The guiding principles that framed our icebreaker in workshop one were repeated throughout our instruction process: "there is no way to do this wrong", and "don't overthink it." Later, participants told us that this framing was helpful, and as they moved through their day and saw objects, places, or interactions that made them think of engagement, they photographed them.

The instructions also included project guidelines (e.g., no people in photos without consent) and a secondary list of sub-prompts to help if people were stuck. These secondary prompts were

tailored to each site and co-developed with site representatives. For example, one of these sub-prompts was adapted from our object icebreaker (e.g., "at your site, the following ideas were discussed when talking about engagement …. pick one from the list, and take a photograph that captures this idea, or shows what it looks like in practice"). Including different types of prompts (Tinkler, 2013) allowed us to tailor sub-prompts to each site while ensuring one consistent prompt across all three sites.

During this workshop, participants took photos, and were invited to continue taking photos at home as homework (if they so desired).

Discussion and Analysis

Photographs were discussed as a group at Empower and PWA, and in a photo-elicited interview format at Casey House (Harper, 2002) in order to accommodate accessibility needs (Switzer, Guta, de Prinse, Chan Carusone, & Strike, 2015). Discussions followed an adapted version of the SHOWED method (Wang & Burris, 1997). In groups, we asked participants to briefly respond to the photograph being shown, prior to hearing thoughts from the photographer. This put a focus on the act of *reading* images, and lent itself to Freirian (1973) ideas of collective meaning-making established through dialogue. During group discussions and interviews we stressed that images could be interpreted in many ways. We asked each participant to write an accompanying narrative about their photo.

Although some participants employed a docu-photo approach (e.g., a photo of a reception area to show the importance of a space), many participants relied on metaphor as a visual strategy (figure 3). For example, Lydia photographed a bike without a wheel to illustrate the way organizations fail young people around accessibility and support. Andrew depicted a bee to show an ecological or symbiotic understanding of people living with HIV and the larger sector. Marc

depicted empty chairs to show the impact of collective grief over time. Other metaphors (e.g., journey as a metaphor - not pictured) were so dominant that they warranted a specific visual analysis as published elsewhere (see: *Journeying Together*).

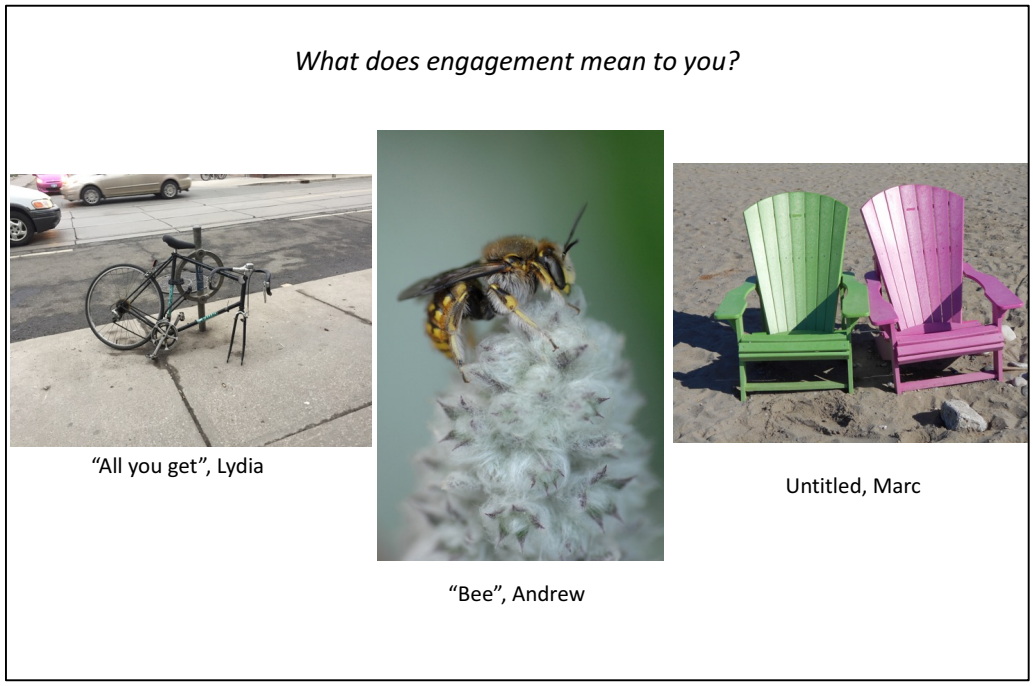

Figure 3 – Working with metaphor – figurative understandings of engagement

Initially, I was surprised by the reliance on the figurative, as our instructions did not deliberatively prompt participants to work with metaphors. However, by reflecting on my pedagogical approach, I realized that icebreakers, open-ended prompts, guidelines, and our focus on photography as a mode of inquiry (i.e., a way of thinking) likely encouraged participants to step beyond the 'docu-photo' photovoice approach, to a more figurative one. Metaphor may have also allowed participants to attend to ethical issues. While participants were permitted to photograph others (with consent), HIV stigma and issues of disclosure pose unique ethical issues for HIV-related visual research, as documented extensively elsewhere (Mitchell, 2011; Schrader, Deering, Zahl, & Wallace, 2011; Switzer et al., 2015; Teti, Murray, Johnson, & Binson, 2012).

Workshop 5 concluded with participants looking *across* their photos to identify common similarities and differences, within their sites. These discussions were used to inform study findings (Switzer et al., 2017). We also discussed how we wanted to exhibit our work. It was during these meetings that the idea for site-specific installations was born.

Preparing for Exhibition

Exhibition is a common element of photovoice (Latz, 2017). These exhibitions often follow a standard approach: photos are often matted or laminated and displayed on tables or walls. In our project, participants chose to create three site-specific photo installations, in addition to displaying their 63 photographs. The installations were not planned in our initial study design. The initial idea of installation was sparked by Tatiana B. Ferguson, a community co-investigator with Empower. She suggested to the group that they exhibit their photographs as a puzzle (figure 4). During the final workshops, at subsequent sites, we shared Empower's idea to demonstrate that participants were not limited in their exhibition options. This encouraged other sites to be imaginative, sparking inspiration for a tree installation and a creative representation of the former hospital building (a house) (figure 5-6). Prior to the exhibit, a smaller group of participants met two to three times (at each site) to further conceptualize, and where necessary, build the installations. At each site, we asked participants, "why a house/puzzle/tree?" to help with the creation process, and provide material for artist statements, as referenced in descriptions below.

The Puzzle

At Empower - an arts-based, youth-led HIV prevention and harm reduction peer education program- participants created a puzzle out of their collective photos (figure 4). For Empower

participants, the puzzle acted as metaphor for collaboration, and coming together across many different communities and program cycles. As reflected by our artist statement: "We often have many diverse identities and experiences in the room: our pieces sometimes fit, and don't fit. A puzzle reminds us of the importance of this difference."

We created a mock puzzle designed from participants' photos to help us plan and conceptualize the installation. In order to create the final puzzle design, participants voted on image options drafted by one of our research assistants, and offered feedback. Ultimately, the group decided on a collage comprised of participants' photos and process photos, and asked for the Empower logo to be placed centrally. Empower participants were highly creative and were interested in ideas of engagement enacted in the *doing* of the work. For them, it was important they the puzzle emphasize the product and process when thinking about engagement. While planning our puzzle, they had many questions: How might the puzzle be used at a workshop or exhibition? How many pieces, and how big? How long should it take to complete? Participants also stressed that it was important that audience members not know what the final image was when they were asked to assemble the puzzle. This became a striking metaphor for engagement. As taken from our artist statement:

> When working on a collective project we often don't know what the end result will be – the end 'image' is a coming together of all of our different parts. It is an adventure that requires that we trust in the process, and give a piece of ourselves. This can be challenging but beautiful work.

Figure 4 – Puzzle Installation: 24" x 36" poster-sized puzzle, 100 pieces

The House.

At Casey House – a sub-acute HIV hospital - clients suggested we build a replica of the former hospital (figure 5). During the study, Casey House was in the process of moving from a small, 13-bed hospital site located in an old house to a new 58,000 square foot purpose-built facility. At first, I was incredulous about the feasibility of this task. Our limited time, participants' accessibility needs, and the complexity of this installation seemed like insurmountable challenges. Some participants were current inpatients at the hospital and were quite ill. However, participants had strong vision, dedication, and were very invested in the planning and execution. A small sub-group led primarily by myself, research assistants, and a community co-investigator, created the blue-print, and first fashioned a 'shell' out of a large cardboard box.

Clients' vision came alive when we began to build together. Together, we transformed participants' photographs into shingles for the roof and wall-paper for the inside (carefully selecting images of the former site for this purpose), and we imagined, constructed, and installed decorative elements (e.g., window boxes and chimneys). Participants added embellishing touches, like flags and stained glass modelled after the original, and crafted from participants' photos. We

wrapped the house in a plastic sheet of bricks, and picked and matched paint colours. We planned landscaping.

When we discussed 'why a house' to represent engagement, participants drew on metaphors, using the materials around us – glue and tape measures – to convey their thoughts. As will be discussed below, it became clear that the house was more than just an architectural rendering. It was a home, representative of belonging. As expressed by our artist statement: "We built it together over 3 weeks, using lots of glue and paste – the bond that holds us together. We measured angles with tape measures, 'to see how far we've come.' It was important to take our time with the house, because 'we've come a long way.' " As we built the house, we talked and laughed about memories in the old space, and hopes for the new building. As one participant expressed, "we want to build this house so that no one forgets."

Figure 5 – House installation – 28" x 32" x 66" house made from cardboard; photographs as shingles, wall-paper, and stained glass.

The Tree

At PWA (an AIDS Service Organization with a large peer-led volunteer program) participants created a tree installation. The tree served as a homage to the "family of HIV" – a theme that was integral to the organization's 30th anniversary which was happening at the time of the study (figure 6). Together we transferred photos onto leaves gathered from the park. Many participants had found support and acceptance at PWA, through their role as peer volunteers. Participants felt that the tree acted as a metaphor for the organization, and the leaves, for the project. As expressed by the artist statement: "The photographs produced would not be possible without the trunk of the PWA family tree. The leaves also represent the diversity of current volunteers, their journey since connecting with the agency, and the nutrients gained from previously fallen leaves."

Beneath the tree were "fallen leaves" with tracings of participants' photographs, which we imprinted using direct sunlight. Themes of light and darkness as connected to personal and organizational journey were significant at this site. At PWA, as we planned for the tree, we had lengthy conversations about the tree as an ecological metaphor for volunteering at the agency, and for the "stages of one's journey through physical and emotional loss, hope, and acceptance." The fallen leaves symbolized the volunteers who had come before, and who had been lost to HIV. Many participants also spoke about the medicinal and healing qualities of leaves, from marijuana plants to greenery used for healing in participants' home countries.

Figure 6 – Photos on leaves (acrylic gel medium) installed onto ornamental tree with lights; photos on fallen leaves 'printed' with direct sunlight

Similar to participants' photographs, these installations would not have emerged had we employed a docu-photo or realist approach to image-making. Our initial conversation about exhibition occurred after participants had looked across their collective photos. These conversations likely primed participants for thinking figuratively about engagement, thus setting the stage for these highly symbolic installations.

Discussion

In 1970, the Museum of Modern Art hosted a photography exhibition entitled "photography into sculpture". Called "photo-sculpture", the artistic works were created from two-dimensional photos transformed into three-dimensional, and interactive forms. As their curatorial statement explained, "Photography into sculpture embraces concerns beyond those of the traditional print, or what may be turned into 'flat' work, and in doing so, seeks to engender a heightened realization that art in photography has to do with interpretation and craftsmanship rather than record-making"

(Bunnell, 1970). Even 50 years ago, it was essential that meaning not be collapsed fixedly into a single photographic image. Similarly, our installations – crafted through a facilitated photovoice process - challenged each of us (participants, researchers, and audience members alike) to re-conceptualize the role of the image in our project.

Metaphor and installation provide many productive possibilities for PVM researchers. These crafted-strategies counter a docu-photo or realist approach to image-making that relies on principles of 'record-making' or evidence as alluded to above. The following section reflects on the methodological implications of our process, and the role of installations and metaphor as a site for synthesis and dialogue, audience reflection, and new theoretical insights.

A site for synthesis, dialogue, and action

By synthesizing many of our conversations into a collective image, installations were a rich site for continuing and deepening conversations about our study topic. We built our installations following a collaborative analysis process that involved participants, community co-investigators and academic researchers in different configurations. Consequently, installations extended our discussions about the significance of each site's photography collection. At PWA, our conversation about the tree as a metaphor for journey was so rich that as a facilitator, I had to cut the conversation forcibly short or else we would not have finished the tree. At Casey House, participants' insistence on the structural elements of the house helped us understand the emotional resonance between the physical space and engagement at this site. (While building, it was not about creating an exact replica of the house, rather, it was what the house symbolized that was important). At Empower, participants' focus on an interactive installation helped us make use of

their expertise (and understandings) as peer educators. These learnings informed project findings as published elsewhere (see: *Journeying Together*).

Our installations also moved conversations about engagement from theory into practice. As we built our installations we spent considerable time thinking about the crafted and interpretive conditions of each piece, in order to create a particular interaction for audience members: policy makers, community members, and staff at community-based organizations. For example, we considered the size and number of pieces so that the Empower puzzle could feasibly be completed within a certain time frame and be useable in workshops or community exhibits. At Casey House, while painting doors and window boxes, we reflected on memories of the past house, and talked about what it meant to pay remembrance to this space. How 'true' did the house have to be to its' original for people to recognize it? What was the link between memory, imagination, and the feelings it evoked?

In contrast to the optic register of photography (i.e., how we see photographs), metaphor involves a "haptic register - what it might mean to feel photographs, and how photographs might, in turn, feel" (Brown & Phu, 2014, p. 14). In our project, many narratives and associated photographs shared painful stories of loss, or the challenges of living life on the margins. For some participants, some images were difficult to witness. Photographs often function like "sacred objects […] providing a tangible connection to a lost place, person, or object" or " a reminder of an elsewhere behind the photograph" (Cvetkovich, 2014, pp. 281-282). While this "tangible connection" was sometimes generative, it could also be upsetting for some. The emotional difficulty that visuals may incite has been identified as an ethical issue when working with PVM (Boydell et al., 2012). As a research project, it was important that we not cause undue harm. The act of transforming individual images into a collective installation was a productive way of

working with what might otherwise be difficult material. The installations, composed as a collection of images, worked as tools to distill otherwise difficult, or complex material into a single encounter – especially when dealing with issues of absence, such as loss and collective grief (a key finding in our work). Working with installation enabled us to keep our sight on the task at hand: creating a way for audience members to interact with, or take up the key themes from our study, rather than focusing on the individual and sometimes painful stories shared through individual photos.

Last, by extending opportunities for participants to reflect on their individual experiences taking and talking about photos, the installations also became a visual site to put knowledge into action. Because the installations were designed explicitly for exhibition, they were a way to collectively evoke praxis (action – reflection – action), an important tenet of photovoice. This collective theorizing can sometimes be ignored in photovoice projects, even though it is often the group-based element that sparks impetus for community change (Liebenberg, 2018). Last, participants took pride in their installations, and were often spokespeople for the installations when on display, both formally and informally. The installations also produced a light-hearted sense of competition between sites, and added to a sense of ownership amongst participants. They quickly became a topic of conversation within respective sites, which may have contributed to the larger community uptake of our project.

Invitations for audience reflection

As a dynamic and interactive form, installation was also a promising way to move findings outside traditional academic settings and to invite audience members to engage differently with the research (Cole & McIntyre, 2008; Reshetnikov, Bogumil, Capous-Desyllas, & Lara, 2018). At

multiple youth conferences, we presented our puzzle to an audience of young people and adult allies. Rather than telling audience members why we built a puzzle, we asked our audience to 'put together the pieces' and tell *us* why they thought a puzzle might symbolize or be a metaphor for youth engagement, thereby enacting the pedagogical quality of the installation. This activity was often accompanied by a standard conference presentation and distributed copies of our report. However, it was only in the *doing* of the puzzle that our findings came to life. Empower participants felt strongly that our installation be interactive. As youth peer-educators, it is only in the *doing* of collaborative work – especially when working across difference towards an unknown outcome – that engagement is born.

In combining the visual, thematic, and textual data, installation art also requires audience members to engage in a dynamic process of interpretation that might not happen with a flat or textual surface (O'Donoghue, 2011). At our community exhibition, our installations were created from the same 67 photos that were exhibited on the walls as 8x10 prints. I watched as audience members physically interacted with installations. I noticed that while most individuals read photo narratives at the same time as they viewed the photo, many participants chose not to read the installation artist statements, or did so only *after* interacting with the installation. While a study on audience perception is beyond the scope of this paper, I suspect that even the photographs portraying metaphorical content (figure 3), when shared with a narrative, may have been read as direct reflections of participants' experiences or understandings. This is not a critique -- at its best, photovoice ought to foreground participant voice. The project was intentionally designed to showcase stakeholders' diverse understandings of engagement in order to encourage organizations to think more deeply about their practices of inclusion. However, perhaps because of their unlikely and collectively-produced form, our installations were an effective strategy in challenging our

audience to not just *consume* participants' understandings, but to ask questions about engagement as a phenomenon, and their involvement in these very processes as either community members or decision-makers (or both).

Through interacting with the installations, audience members were provided with a window or door that moves one from questions of 'what is this?' to 'what could this be?' As participants peaked through windows of the house, shuffled puzzle pieces, or walked around the tree to see photographic leaves from different angles, they were met with a more sensory and immersive experience. As O'Donoghue (2011) writes, "[T]he installation requires viewers to engage in a dynamic process of meaning-making that is contingent upon searching for and making connections between what is represented, what is suggested, and what is imagined. […] In this type of work, meaning is generated through interaction and negotiation with the work" (p644, 647-648). Installations did not serve as direct reflections on reality. The 67 photos were the same, but the *form* that the installations took left the meaning much more open.

Working with installation can also be a generative site to move findings into practice. It is often not feasible to show 63 photographs at a conference or workshop. Created from the collective photos of each site, our installations included all of our exhibited photos and crystallized our key findings into three memorable images that invited audiences to understand both the summative and affective dimensions of findings. For example, during a community panel, one of our community-investigators spoke evocatively to an audience of service providers and community members about the importance of chosen family and 'home' for long-term HIV survivors. He encouraged organizations to dismantle pre-conceived ideas and think "outside the box" when thinking about engagement. His speech was very powerful, but it was only when he drew on the metaphor of the house - pointing to the bricks and mortar of the cardboard house (initially built

from a giant cardboard box) – that his point 'arrived home.' It was also in this moment that I understood the degree to which many participants felt ownership over the installations and the project.

A Site for Theorizing: Grappling with Engagement

How might practitioners think more deeply about the role of the image, and the methodological design of photovoice studies? In our project, I was invested in co-creating a space where we could co-theorize and grapple with what we meant by the term and practice of engagement. While I came with my own theoretical orientations, I was interested in the journey we would take together. Participants' interest in installation and metaphor is particularly apt, given my interest in the 'beyond' of engagement work, as alluded to above. I could never have guessed that this is where we would have ended up.

In the text *Art Beyond Itself*, García Canclini (2014) challenges us to think carefully about the role of art, and in particular metaphor for *working against* easy, simple answers. For Canclini (2014), the role of the artist is not to supply missing information but instead to construct "spaces where we can see and think in a different way" (p. 115). For Canclini, metaphor can accomplish this by getting something to remain unresolved. Our installations and metaphorical images translated ideas without nailing down any one particular meaning. Instead of fixing engagement as either a means or an end, as a curated collection, participants' photographs and our co-produced installations became a way for us (myself, participants, and audience members) to ask new questions about what is possible when thinking about engagement within community-based HIV organizations. The installations and metaphorical images were certainly not what one might expect, given how engagement is often discussed in health as a biomedical, individual and

behavior-based phenomenon (Barello, Graffigna, & Vegni, 2012; Chiu, 2008). Our project didn't fit – and this was precisely its strength.

This is particularly important given the initial aims and the larger goals for this project: to encourage organizations to think more deeply, relationally, and in nuanced ways about centering the voices and lived experiences of people living with HIV in programming or policy change. We needed to shift the frame. Metaphor's ability to create ruptures, work outside language, and submit to what Barthes calls the "intractable" passage is a way of achieving what Sandoval (2000) refers to as differential consciousness - a technology of the *Methodology of the Oppressed*. Drawing on Barthes, Sandoval argues that this strategy can be used to deconstruct dominant ideologies that appear as natural. Engagement as an instrumental, apolitical means or a fixed end is of these ideologies.

Audience members frequently commented how surprised they were by how much emotion was evoked when reading the images and narratives. The non-fixity of meaning in metaphor is what helps to carry an image's emotional impact along. In other words, we are convinced *because* it is not rational (McKay, 2001). Similar to Barthes (2003) punctum, that which "wounds" or "pricks me" (p. 25), metaphor pulls the viewer into a subjective experience. As McKay argues, metaphor is "a form of knowing which 'counters the primordial grasp' "(McKay, 2001, p. 26, drawing on Levinas, italics original). I am regularly haunted by the image of the chairs in figure 3. The empty chairs are symbolic of the loss we encountered in the project. The image, and its associated metaphor, pricks and bruises me. Images like this one are lodged in my memory. But even this understanding of loss can't quite be articulated – it floats. I cannot grasp it. It is not "a *vestige* of the other, but a *translation* of it" (McKay, 2001, p. 28, *italics original*).

Conclusion

The materiality of an image has profound consequences for how it is interpreted (Gubrium & Harper, 2013; Mitchell, 2011). And yet, there has been little investigation into alternative formats for photovoice exhibition, or the crafted nature of participants' images. While community exhibits in photovoice are common, rarely do scholars describe whether or *how* participants are involved in the development of exhibits (Evans-Agnew & Rosemberg, 2016). This is surprising given photovoice's focus on 'empowerment,' participation, and social change. If we follow these tenets, practitioners ought to remain open to new ways for images to be seen across different sites, audiences, and modalities. How might we think differently about the role of images in our photovoice projects? Not as vehicles for supplying missing information, but as "the invention of cognitive openings or networks" (García Canclini, 2014, p. 77)? How do we prioritize the exhibit in photovoice, so that images might be seen 'over, and over, and over again' (Mitchell, 2015)?

In this article, I explored the methodological and pedagogical elements of a photovoice project that focused on 'engagement' in the HIV sector. This project led to the creation of 67 participant-created photographs that relied heavily on metaphor as a visual strategy, and three site-specific installations created explicitly for exhibition. By reflecting on my theoretical orientations to photography, and our methodological and pedagogical process, I show how certain design elements led to the development of installations, and photographs that relied on metaphor as a crafted strategy. By moving away from docu-photo approaches to photovoice, installation and metaphor may open up new possibilities for photovoice practitioners. As one policy maker said to me when thinking about peer programming at her organization: "this work is making us think differently." Revisiting the role of the image in photovoice studies may allow us to fashion photovoice projects not to reflect on pre-existing ideas, but to create new ones.

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fold over,
and over, and
over
again

Figure 1 – Working in the fold, Installation made from 18 folded photographs and sewn together

Figure 2 – Video Still

This installation is composed of 18 photographs folded into individual spinning octahedrons. Each octahedron is folded by hand, over the course of 18 months of field work. Together, they represent my role as a facilitator in this collaborative project, as well as my arrival at the 'beyond' of engagement. As discussed in the subsequent chapter, the facilitator in community-engaged projects will shape the very contours of community-engaged projects both consciously and unconsciously.

The photographs were taken over the larger course of my doctoral program, as a way for me to visually make sense of and trace the evolution of my thinking. In the mobile, the photographic octahedrons are organized into 3 inter-related strands: 1) the psychic investments I bring to community-engaged projects – and the deep work one must do to reflexively account for these investments (an impossible process); 2) what one might be trying to 'aim' for in community engagement (i.e., one's ideological orientations to engagement) – in my case, the 'beyond' of engagement; and 3) the importance of grounding one-self while holding space for others. For me, this is visually marked by moments of connection with land. The order of the strands is important. The middle strand (2) – what we are aiming for – is bolstered by both our psychic investments (1) (our desires) and what grounds us (3). The categorizing and ordering of photographs into strand was an intuitive and analytic process.

While one can never be fully transparent in one's desires[1], building the mobile helped me "seriously consider what is at stake socially and psychically in [my] pedagogical encounters" (Todd, 1997, p. 4). The mobile and my poetry was a way to reflexively make sense of my affective investments. As Ahmed (2000) reminds us – nodding to Felman and Laub (1992) - "encounters always conceal as much as they reveal: they involve trauma, scars, wounds and tears that are

[1] Here, I see desire as affective, in flux, and conscious and unconscious; it is neither revelatory or repressive, but creative in that it produces both pedagogy and subjects (Zembylas, 2007).

impossible to forget … or to present or to speak." As she continues these encounters "affect how we arrive or face each other" (p. 158). Much like these three lines of thought, the strands often get tangled up. They are not singular, self-contained processes. In the process of facilitating community-engaged work, we also may get tangled up. There are many collisions. As hooks (1994) writes, "[m]aking this theory is the challenge before us. For in its production lies the hope of our liberation, in its production lies the possibility of naming all our pain – of making our hurt go away" (p. 74).

To capture the messiness and dynamic nature of this process, I chose to film the mobile, rather than present it as a 3-dimensional, static object (or 2-dimensional photograph). The moving nature of the mobile (rather than a fixed image) also speaks to the dynamic, and tangled-up nature of engagement processes. I have hung it on a tree, in order to pay tribute to, and acknowledge the land on which my research is situated, and those who have cared for this land in present, and in the past: the Mississauga's of the New Credit Nation; the Huron Wendat, the Seneca, and Petun First Nations. The images in the third strand of octahedron are representative of my own relationship to the land, as a place of healing, reflection, and self-care during this journey.

Stills and photographs are presented in figure 1. The installation as video can be viewed as attached. I will return to a discussion of the mobile and the messiness of collaborative, participatory research in the subsequent chapter.

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Chapter Six

Discussion

"What moves us, what makes us feel, is also that which holds us in place, or gives us a dwelling place" - Ahmed (2004), p. 11

"There is imaginative work to be done" - McKay (2001), p. 33

This is a dissertation about community engagement. But it is also about home and belonging. About loss and grief. About a journey into an unfixed, unknown. About resistance in what Cruz (2011) calls "tight spaces." About navigating the bumpy ride of collaborative work.

This study created a space of imaginative possibility for individuals - including myself - to think about, and visualize their own conceptualizations of engagement. Included in this dissertation are three articles that explore different methodological and substantive analyses of engagement. To reflect the larger collaborative and action-based aims of the project, I also include elements from my own creative practice, and an accessible community report created for service providers, and community members. Together, the outputs illustrate that the discursive and practical application of engagement is quite complex.

In this dissertation, I respond to the following research questions:

1. Using case study analysis and photovoice, how do different stakeholders (clients, peers, volunteers, service providers, clinicians, etc.) conceptualize community engagement *within* and *across* three different HIV programming or service delivery organizations How are these different conceptions of community engagement shaped contextual or socio-political/historical-factors *within* and *across* different HIV organizational sites?

2. When engaging different stakeholders from HIV community-based organizations in a participatory photography project, what new conditions of possibility are created for theorizing engagement? In other words, using my own role as a participatory visual methods researcher/facilitator, and artist as a site for theorizing, how might this project offer new ways of thinking about engagement?

3. How might using photovoice to explore engagement contribute methodological insights on the design and execution of future participatory visual methods projects?

The first question(s) is empirical. It overlaps with larger *Picturing Participation* study objectives. It was informed by consultations with community partners. This question takes up 'how different stakeholders understand or conceptualize engagement' and the contextual factors which shape these conceptions. I respond to this question most-squarely in *Journeying Together* and *Youth Talk Back*. *Journeying Together* was written in collaboration with other team members however, I took the lead as first author and did a significant portion of the analytic work in different variations. My article *Youth Talk Back* also responds to this question; however, it was not written collaboratively. Although I member-checked findings with participants, and some of the analytic work done within the paper was conducted collaboratively as part of the photovoice process, the sole-authored approach to this paper allowed me to take a slightly more critical and theoretical stance. In these chapters, I make the case for precision regarding engagement practices, by discussing the various ways stakeholders conceptualized community engagement within and across sites. Each article showcases a different focus thematically but also methodologically: cross site analysis; analysis within and across sites; and an in-depth site analysis.

The second and third questions are theoretical and methodological. They are distinct from (but informed by) the goals of the larger CBPR project. The second question explores 'what new relations or possibilities emerge' if I approach engagement in a particular way. The third question is related but focuses specifically on the field of participatory visual methods. As facilitators or researchers, our ideological positions (conscious or not) will shape the way engagement processes are designed, and executed. For this reason, I make my pedagogical and theoretical fingerprints explicitly clear in *New Directions for Photovoice*[1]. In this chapter, I challenge the way in which

[1] My theoretical orientation towards feminist, qualitative research stipulates an understanding of research that is always and *already* situated, partial and subjective.

photovoice scholarship often takes the image as a 'truth artifact' rather than a deliberately-crafted representation. I explore how I co-designed and co-facilitated the project – as influenced by my theoretical orientation to engagement – and illustrate how these orientations created the necessary conditions for participants to produce site-specific photo installations, and images utilizing metaphor as a visual strategy. Here, I elaborate on how the installations and images provided participatory visual methods scholars new opportunities for: inviting audience reflection, acting as a site for inquiry, and theoretical reflection. This article also briefly touches on research question two as I nod to my conception of engagement as not an end, or a means but a beyond.

I will return to the concept of engagement as a beyond, and this research question in this chapter, where I reflect on my dissertation as a whole in order to explore what new conditions of possibility are created for theorizing engagement. I propose a new way to theorize engagement as an affective, dynamic and pedagogical (and thus, relational and ethical) process. Using my own role as a researcher/facilitator and artist as a site for theorizing, I argue that rather than seeing engagement as an end, or a means, there are conceptual possibilities for thinking of engagement as a beyond. Similar to our site-specific installations, the creation of the mobile assisted me in thinking through many of the theoretical implications of this work. Thus, I begin this discussion by reflecting on insights gained through my creative practice. I then return to my initial diagram of participation in chapter one, and extend it in light of my dissertation. In doing so, I reflect on the "bumpy" nature of this dissertation, in order to extrapolate on the relationship between engagement, difference, and power. I conclude with reflection on strengths, limitations, and future areas of research.

Working in the fold

I began my interest in folding photographs after enrolling in a workshop called "Cut, scratch and fold: how to lovingly degrade your photographs" at Gallery 44, led by artist Jessica Thalmann. The workshop instructed participants on how to physically manipulate images by playing with their physical or chemical properties. I was intellectually and creatively fascinated by the act and the thought of folding. Not only did it align with my theoretical interests in disrupting the 'truth effect' of the photograph, but it was a way for me to create something new out of previously-crafted material. When I began my field work, and began supporting other people in their photography pursuits I had lost interest in taking my own photographs. At first, I was concerned. My own photographic practice was supposed to be a key element of my dissertation!

In my first three years of my doctoral work, I often turned to photography as a form of visual inquiry (Weber, 2008). Taking photographs helped me work through conceptual material, but also my own psychic investments in my work. As Narayan (1997) writes, this "enables one to see, with humility, and gratitude and pain, how much one has been shaped by one's contexts, to sense both the extent and the boundaries of one's vision, to see how circumstances can circumscribe as well as inspire, and to become self-aware to some extent of one's perspectives on things" (p.3)

photo practice

Click the shutter
eye in the (w)hole
the me and the not me.
a photo:
a trace in time,
fixed - almost
but not quite.

sight, unseen

shadow light
striped,
stripped
across my page -- in
a second, the sun
is gone.
irretrievably forgotten.

However, creating and sharing my photographs had implications. If I was to share these photographs, I would have to unpack them. Many of these images were deeply personal. Completing a dissertation required me to undo my own internalized beliefs about my abilities and my own experiences of trauma. Could I really do it? Did I have what I took? When I was a teenager, I sustained an acquired brain injury that resulted in many academic (and personal challenges). Years of conditioning from psychologists and guidance counsellors rang in my head. There was much (inner)-work to be done. I often became undone or unhinged during my doctoral program – a process referred to during a poem I shared in one of my comprehensives. This was a profoundly challenging process.

I fold
into myself, bending
at stitched seams.
Like a paper
crease I have
been folded
10 times over
and over, again

I know these actions well,[2]
repeated, they
circuit into ligaments
and connective tissue,
fuse over folds
a mound in the carpet,
familiar.

[2] "Through repeating some gestures and not others, or through being oriented in some directions and not others, bodies become contorted; they get twisted into shapes that enable some action only in so far as they restrict capacity for other kinds of action" (Ahmed, 2004, p. 145).

I was uncomfortable sharing these photographs (and some of my poems) in a way that would be owned by an academic institution. My participants shared much with me but they also strategically held things back. I wanted to hold something back but wasn't sure how I might do this. I started folding octahedrons, serendipitously. The shape seemed easy enough, and was a useful way to practice working with different papers. I enjoyed the almost-meditative and repetitive nature of the folds. I folded in the evenings. I folded when I went away. This was a difficult project. The loss and grief and emotional weight of holding people's stories often weighed heavy on me. We lost two participants during the study -- both in untimely ways and in one-case, very tragically. Some of my participants I had also worked with for many years. For a variety of personal and ethical reasons, many of the poems I wrote about the weight of grief and loss (my own and others) were challenging to share in the dissertation. They blurred the lines of ethics: when my story rubs up against someone else's, which stories are mine to tell?

Hence, the fold became an crafted strategy - a way of getting something to stay unresolved as García Canclini (2014) suggests. The mobile as installation – composed of 18 images that the viewer can't quite make out symbolically represents this omission, by nodding to the *affective* value of testimony, rather than the details of it (Laub, 1991). As I folded and unfolded the photos, the rhythm helped me process the grief and affective entanglements that result from doing deep, community-engaged work. Some photographs were more emotionally and physically challenging to fold than others. I had to undo and redo the folds many times. However, in the end, the photographs with the deepest creases were the ones that formed together the strongest. It was through this process that I learned that there is strength in the fold. Thus, in an unexpected turn, what was supposed to be a simple origami exercise resulted in a creative and embodied way to process the affective impact of my field work and soon became the fourth installation of this

project. I stumbled across an online site on sacred geometry and learned that octahedrons were representative of healing, and journey. Shortly after, I had a conversation with one of my co-investigators who insisted that the Empower photos must be seen from all angles. Since this was a participatory project, she insisted that people viewing the images needed to "participate in the image." This conversation led to the creation of the co-produced site-specific installations. Six months later, journey emerged as a key theme in our work.

While the connection now seems obvious, at the time I couldn't have been more surprised. Beginning with my first fold, it took me twenty months to build this mobile. If I counted the photographs within it, it took me 4 years and 7 months. The first photograph was taken in 2014 as part of a digital story I crafted during my first year of my PhD, where I explored my own relationship to HIV and queerness through a complicated family history. The story opens up to the line, "How do you mourn someone you've never met?". On the screen, is a shot of the Pacific Ocean with the words "Remember" drawn out in the sand. While filming the digital story, I picked up a piece of driftwood and carried it back to Ontario, as a memento. The driftwood now forms the base of this mobile. It took over a year to determine how to install the mobile. Poignantly, the driftwood was there all along.

As Davis Halifax (2004) writes: "There is always something beyond that which is *not yet* seen, *not yet* in view" (italics mine, p.183). Somethings, much like this dissertation and the relationships it was built on, are meant to take time. Sometimes the connections don't emerge until much later. Through engaging with my creative practice (photographs, the mobile, digital story), I was able to reflect on the way in which my own biography shows up in my present work and wrestle with the theoretical tensions of engagement in a more embodied, intuitive way. These past/present collisions are integral to understanding my role as a facilitator in processes of

engagement not only because I play a significant role in directing, holding, and shaping spaces (and the power that comes with this), but because engagement is a relational act in being with self and Others. There is accountability here, not only for facilitators but for all of us involved in these processes. I now turn to my theoretical re-working of engagement as a beyond (the 'not yet') and the contributions of this dissertation.

Re-theorizing Engagement

As discussed throughout, while there is significant scholarship on participation (Bishop, 2012; Chiu, 2008; Cooke & Kothari, 2001; Cornwall, 2011), the concept of community engagement – and its relationship to participation – is particularly untheorized. Thus, one of the aims of this dissertation was to "take apart the conceptual orderings that conceal the difficult question" of engagement and participation itself (Britzman, 1998, p. 80). There is limited scholarship (that I know of) that puts this literature into dialogue with engagement in a systematic way.

Figure 1 presents a diagrammatic overview of the relationship between participation and engagement as a field of study. Composed from the literature and empirical evidence, it illustrates the different ways in which future research might tease apart facets of participation and engagement. Thus, this diagram – and the theory behind it - is a key contribution of this dissertation. Despite the interchangeability of terms, scholarship on community engagement in health rarely addresses critical work on participation, preferring to focus on the impact or processes and tensions of community-engaged processes rather than its conceptual trappings (S. M. Ahmed & Palermo, 2010; Attree et al., 2011; Coulter, 2012; Higgs, Moore, & Aitken, 2006; Kendall et al., 2017). There is a vital need to put this scholarship in dialogue with each other. As echoed throughout, community-engaged processes can serve very different ends. Figure 1 is modelled

after a bulls-eye. As symbolized by the arrows, community engagement is something practitioners may often 'aim' for. Sometimes they achieve it, but often, they miss their mark. I am one of these practitioners.

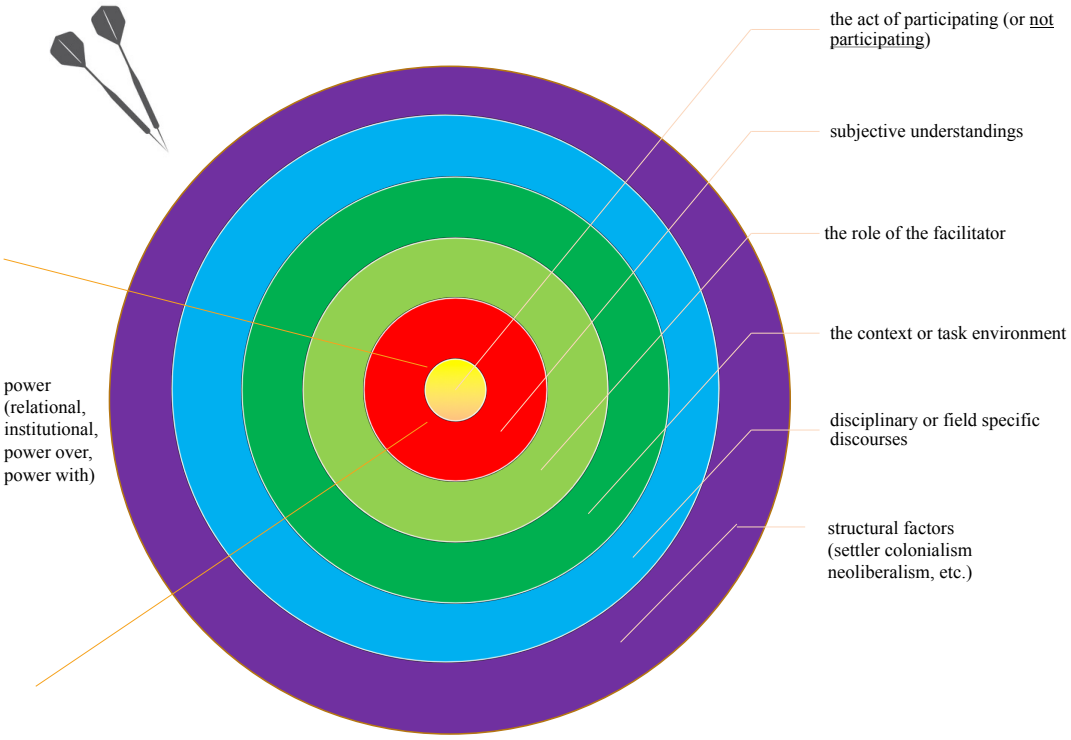

Figure 1 - Dimensions of community engagement

Let's start in the yellow centre: the act of participating. As defined throughout, participation includes the act of participating, whereas engagement relates to how people subjectively understand their participation (or their role in bringing this participation about). Most scholarship to-date has focused on the individual participating, as discussed in the introduction. Critical

scholarship has broadened this lens to ask the questions of who, why, how and to what ends? These are related to the questions of power that radiate outwards from the centre.

What my work adds to this specific area, is the study of non-participation. As explored in *Youth Talk Back*, it is imperative that we move non-participation from its ignored location on the bottom-rung of Arnstein (1969) and Hart's (1997, 2008) often-cited participation ladders to a more central place of discussion. Who participates (and who does not) is not a matter of happenstance, nor is it simply a result of improper outreach. Participation is often contoured by asymmetries in class, race, sexual orientation, ability, gender, and Indigeneity (Dhillon, 2017; Fox et al., 2010; Kwon, 2013). In *Youth Talk Back,* I argue that non-participation must be seen as a productive component of our engagement frameworks. There may be a variety of valid reasons why people choose not to participate. Sometimes this may be an act of resistance, albeit subtle or hidden. Sometimes, it may be out of self-preservation, self-determination, or self-care. Sometimes participatory processes are not designed with participants needs or best interests in mind. And sometimes, the ongoing stress of people's lives may leave them too drained. The call to participation also produces subjects (e.g., deviant subjects), as argued by myself and others (Braun & Schultz, 2010; Guta, Flicker, & Roche, 2013). Non-participation is also addressed in our community report.

In the second circle (red), are the various ways in which stakeholders in my study make-sense of, or discuss their understandings or experiences of engagement. Many scholars have identified that engagement and participation are rather vague, and abstract terms (Chiu, 2008; Cornwall, 2008; Head, 2007). In my dissertation, my co-authors and I identified seven key dimensions that may support organizations in facilitating conversations about engagement, as

discussed in chapter two. These themes or dimensions may vary across sector or organization, however, as discussed in the chapter, many are transferable across the social service sector.

For example, in *Journeying Together*, my co-authors and I illustrate how discussing engagement through the lens of journey may be a generative site for organizations to discuss engagement practices. It may shift conversations about engagement from an end or means, to a more dynamic or relational process. Journey also implies a temporal component, with a past, present, and future. This is not to suggest a linear or teleological process, but rather to stress that when it comes to engagement we are doing this *work together*, *in and over time*, with an attention to some future unknown outcome. This is important because without acknowledging our respective journeys as a crucial element of engagement work, we run the risk of falling into many of the critiques raised in the introduction: an over-reliance on technocratic, positivist or behaviourist ways of approaching engagement that fail to account for larger structural issues of power.

The pedagogical components of engagement must also be considered. This is marked by the light green circle. By pedagogical, I mean a relational and ethical process that is shaped by our conscious or unconscious desire to "push against" the subjectivity of another (Gaztambide-Fernández & Matute, 2013). In other words, engagement is always ideological, because it always involves expectations – whether we acknowledge them or not. Pedagogy (like engagement) is inherently directive. To quote Zembylas (2007): "without desire, there is no pedagogy" (p. 338). As explored with my mobile, this is shaped by relationship to "one's biography, present circumstances, deep commitments, affective investments, social contexts and conflicting discourses about what it means" to do this work (Britzman, 2012, p. 34). To draw on Ahmed (2014), this is also related to will: the will to participate, what it means when one does not participate (i.e., to be perceived as willfull); and the will of the facilitator in willing others to will.

As pedagogical phenomenon, engagement always involves more than one person, thus it is enacted in relationship and bound up with an understanding of the Other (Gaztambide-Fernández & Matute, 2013). Within dominant discourses on engagement, engagement processes are often framed through the language of 'different perspectives' and 'different voices.' However, it is often through participatory processes that *produce* difference, either by accident or intention. Ahmed (2000) describes that any politics of difference must view difference as not as *already* there but produced *through* an encounter. Individuals do not come to engagement processes as contained representations of "difference" (i.e., diverse constituents), but rather, as subjects created as different *through and in relationship to* an encounter. These encounters might be a moment during a team meeting, a workshop, or in casual conversation. As one of my participants wisely probed during a workshop: "Is it ambitious to imagine youth [HIV prevention] programming that is all-encompassing of everything that we are? … by virtue of being all the different ways we come into programming, I think we're *already* fragmented in many ways…" In other words, each time a community-led project invites a particular 'community' (e.g., youth) to participate, the project demarcates or "fragments" one part of one's identity from another.

Next, is the dark green circle: the context of the task environment. Like participation, engagement must always be understood contextually (Jenkins & Carpentier, 2013; Moose, 2001). Without the context, it bears little meaning. In this study, the context was the institutional environment. We used case study design in order to locate the unit of analysis on organizational sites, thus privileging this context. Looking within and across organizations helped us tease apart the importance of organizational contexts in shaping these understandings (see: *Journeying Together*).

In the blue circle, I acknowledge the way field-specific discourses shape understandings of engagement within organizations or other contexts. In this dissertation, I addressed how the history of HIV activism influenced the development and integration of GIPA/MEPA principles, which have informed how engagement has been taken up. In our study, these principles were more intelligible in AIDS Service Organizations than other HIV community-based organizations or projects. Although outside the scope of this dissertation, other field specific discourses include the way participation functions within socially-engaged art (Bishop, 2006, 2012) or participatory visual methods (Switzer, 2018) as discussed in chapter one. Field specific discourses are also addressed in *Youth Talk Back*. In this chapter, I broaden my analysis – with help from Empower participants – to explore how the logic of participation operates within the youth sector versus a specific organization.

This leads to the outer ring of the bulls-eye: the impacts of settler-colonialism and neoliberalism in framing engagement. I take up this ring most explicitly in *Youth Talk Back* when I explore the way in which neoliberal and settler-colonial frames have influenced dominant participation typologies. I make a case for non-participation and argue that young people's acts of not participating (or participating on their own terms) may be seen as acts of resistance. Dominant narratives of engagement as an end or a means come with their own moral trappings – especially when called on by the state. This ring does not only reference to structural issues (i.e., poverty) but the way in which structural discourses impact our narratives (which then impact material issues). For example, as Veracini (2010) reminds us (speaking specifically to narratives that inform settler colonialism): "Narratives are a fundamental part of everyday life, and their construction constitutes an act that allows nations, communities and individuals to make sense of the world" (p. 97).

Which bodies are most frequently targeted by community engagement initiatives? This is not an issue that is only contained to the field of health. Participatory art projects (including those that rely on the visual) are often funded to address 'social problems' in low-income neighborhoods, thus functioning as another foil for gentrification or 'revitalization' (Hutcheson, 2014), or what Ford-Smith (2001) describes as "a brightly packaged form of welfare" used as a means for justifying traditional narratives of the nation–state (p .13). In Toronto, these same low-income neighborhood are most likely to be stratified by race (Contenta, 2018). As explored throughout, these participatory initiatives often put the burden of responsibility back onto individuals and communities and take attention away from the importance of larger state responses to inequity. Goldberg (2009) explains that under neoliberalism, "modern state and regional arrangements have come to form, fashion, make and mold – in short, how they manage – their heterogeneous populations (p. 328). In certain configurations, the larger structure of community engagement processes may be one of these arrangements.

It is telling that while literature is beginning to surface on some of these problematics (see: Dhillon, 2017) conversations about settler colonialism and engagement are disturbingly absent.[3] Dhillon (2017) speaks to the role of participatory strategies (used under the umbrella of 'community engagement') in intervening in, and managing the lives of Indigenous youth:

> [It] is short sited and dangerous to assume that the settler state is simply going to step in and right its own wrongs – regardless of how many more inquiries are called or reports commissioned or participatory strategies developed. If, as Andrea Smith and Taiaiake Alfred have warned, the state is the chief perpetrator of violence in Indigenous nations, its institutions, agencies, and programs cannot be the place where justice is found, nor can strategies for eradicating colonial violence and fostering decolonial cultures be rooted in these power structures (p. 239-240).

[3] To implicate myself in this process, I had only considered the connections superficially until my committee asked me very pointed questions about how processes of community engagement might be implicated with settler colonialism. I am grateful for this pointed question.

One might apply Dhillon's work to the wider reach of the settler-colonial state. The language of 'community engagement' may be used for very different ends. Many decisions that protect settler-colonial and neoliberal interests can be justified in the name of an instrumentalized community engagement where diverse constituents come to a table, devoid of socio-historical power relations. As long as community engagement box has been checked on a policy document, it gives the state (or an organization) free-reign when justifying many decisions.

Recall the constitutive hierarchies of settler colonialism (i.e., those that appear natural)[4] that are cloaked behind the participation typologies, addressed in *Youth Talk Back*. As Veracini (2010) tells us: "The more [settler colonialism] goes without saying, the better [settler colonialism] covers its tracks." (p. 15). This disembodied, apolitical, and individualistic frame of dominant community engagement discourse neutralizes very violent histories, and contemporary realities. For example, read through Vericini's lens, one might ask in what ways hegemonic engagement narratives might actually enable the continued (unwanted) access to Indigenous communities and lands (in the name of research or participatory programs)? Or, what ways might shallow community consultation processes allow public health agencies or governments to make sweeping decisions that are not actually in-line with community needs and desires? In a recent talk, Sandy Grande (2018) drew on the politics of refusal (nodding to the work of Simpson (2014) and Coulthard, 2014) to provocatively ask the audience to reconsider the frame of inclusion. As she provoked, for those individuals who have been historically excluded from institutions, what if the only thing more violent than being excluded from the state was to be "invited into its fold"? In other words, under a liberal lens of inclusion, how might the invitation to take part actually quell resistance, and extend the reach and arm of the white supremacist, settler-colonial project?

[4] Here, I am drawing on the work of Coulthard (2014).

The disavowal of the violence of settler colonialism (both material and discursive) is one of the ways settler colonialism continues to operate (Veracini, 2010). As Veracini (2010) continues, settler colonialism has a "mimetic character and that recurrent need to disavow produces a circumstance where the actual operation of settler colonial practices is concealed behind other occurrences" (p.14). Recall Morales (2013) poem in chapter one. Writing as a Puerto Rican survivor of stroke, cancer, and other chronic illnesses, she writes: "If I write about our bodies I am writing about the land and what has been done to it." As a fixed end, or an instrumentalized means, the relational elements of engagement – like the impact of resource extraction on people's health, or the dispossession of people from their lands– get erased. Furthermore, drawing on chapter two (*Journeying Together*), how the various actors in community engagement processes arrive at this moment (the histories, the moments of contestation, etc.) are also not intelligible. This includes the very social movements that lobbied for public participation. In the case of the HIV epidemic, this includes those holding silence=death banners in high demand that they would not be erased.

The bulls-eye: Hitting or missing our mark

We do not *do* engagement alone, nor do we *do* engagement in a vacuum. We do this work with, amongst, and between people with different histories and social identities, and often within institutions between people with different roles. Broadening our understanding of community engagement to include both participation and the 'outer rings' is what makes community engagement what it is. Participation (the action) is also discursive and evoked in different contexts, however, in our current era it is not mobilized to the same extent as community engagement. The buzz word of community engagement can be found across policy documents, mission statements, funding calls, and university branding platforms. It is for this reason that community-engaged

practitioners (myself included) must continue to consider, what are aiming for in this initiative? What conditions are we resisting, or trying to bring into being? By suggesting that one might hit or miss our mark when it comes to engagement is not to fix it as an end, but to keep these questions at our fingertips.

As illustrated throughout, community engagement processes are not neutral. They can be used to both reinforce and subvert systems of oppression. Sometimes at the same time. As a bulls-eye, figure 1 asks: What does community engagement *do*? What does it enable? Who are the communities that academics so badly want to access in CBPR efforts? Which bodies are rendered non-compliant or deviant when not wanting to participate? These are often forgotten questions. This active act of forgetting (the silences and omissions) is important – especially if we zoom out to look at the large narratives and structures at a play. It is telling that community engagement as a discourse has become so normalized and unquestioned (a holy grail of sorts) within the field of community health. The quick uptake of the state is no accident.

As practitioners, we often fail to think through the harms we may be causing, even in the context of projects carried out in the service of social justice. What happens when our arrows are so loaded with 'well-intentioned' desires that we aim to hit the bulls-eye but miss entirely? As Coulthard (2014) argues:

> By ignoring or downplaying the injustice of colonial dispossession, critical theory and left political strategy not only risks becoming complicit in the very structures and processes of domination that it ought to oppose, but it also risks overlooking what could *prove to be invaluable glimpses* into the ethical practices and preconditions required for the construction of a more just and sustainable world order (italics mine, p. 12).

Many of my participants provided such invaluable glimpses. For example, as briefly discussed in the community report (chapter two), participants identified that any successful engagement process must honour relationships – to one self, to one another, and to the land. I would argue that a

relational, dynamic and affective focus on engagement (i.e., engagement as happening between multiple actors) might enable many other glimpses.

What might a conversation about the complexities of community engagement enable? Whose voices might these additional concentric circles elevate? In a context where engagement is increasingly measured, ranked, and scored in funding applications, what does this diagram turn on its head? And, what assumptions does it leave unchecked?[5] These conversations are important because they conceptually enable a recognition that participating (or choosing not to), given our unequal landscape, is not always what it always looks like. It is for this reason that many conversations about the specificities of engagement are so important. These specificities – be it the context of ongoing grief and loss, or what it means to be seen in an organization as a woman of colour, or a youth with disabilities – move engagement as a "fuzzy" term employed by funders, policy-makers and academics (myself included) from a policy document or a paper, into a concrete, fleshy, practice.

Re-conceptualizing engagement as a 'beyond'

As many of my participants generously taught me, it is not what engagement *is* that is most important, but rather, *what it could be*. What might it do to our conceptions and practices, to consider engagement not as an end or a means but a beyond? This is one of the primary theoretical contributions of my dissertation.

[5] During my doctoral defence, my external, Eve Tuck pointed out that the diagram of a bulls-eye relies on conceptions of scale (i.e., a measurement system that invites comparison, or growth). Scale, she argued, is still a settler-colonial construct. For example, in these types of scaled diagrams, why are structural factors such as settler colonialism always placed on the outer-ring and not in the middle? This type of scaled diagram is so visually pervasive that I had not questioned whether it may also replicate settler-colonial frames. Echoing Veracini (2010) again: "The more [settler colonialism] goes without saying, the better it covers its tracks." (p. 15). These hierarchies become naturalized. While I was not required to attend to this critique in my dissertation, I am grateful for this conversation, and look forward to revisiting this diagram in subsequent work.

In my article, *New Directions for Photovoice* I discuss the methodology behind the project, and my role as a facilitator within it (the pedagogy of community engagement). I share how I - with the help of my team - designed and implemented our participatory process that led to the creation of 67 exhibited images that relied heavily of metaphor as a crafted strategy and 3 site-specific installations. Once exhibited, these installations (and the way in which they were exhibited in a space with many community members and service providers) helped challenge audience members to think differently about the possibilities of engagement. They encouraged audience members to "put themselves in the image" (to colloquially draw on Joe Spence's (1986) work) and countered individualist, behaviorist views of engagement as a means or an end. It is in the production and exhibition of these installations and the conversations they engendered that viewers might tangibly see the conceptual *beyond* of this dissertation work – what Sandoval (2000) calls the "obtuse third meaning that shimmers beyond all that we know" (p. 145). This is also where audience members, participants, and myself *affectively* felt the impact of our conversations. This affective dimension was not in the room, nor in the objects. Rather, it was in the relationship *between* objects and people: *between* installation and audience member; *between* exhibit and hospital; and *between* the differently-situated bodies in the room. It is in the between and beyond that this work arrived home.

During our community exhibition, the large cafeteria of the newly-designed hospital was bustling with the energy of almost 100 people who came through the doors: people living with HIV, young people (some living with, and some affected by HIV), people who use drugs and those who do not, policy makers, community artists, researchers and service providers (some who also had lived experience). People of a variety of ages, serostatuses, races and ethnicities, abilities, and gender identities attended. It was an exceptionally diverse crowd that was reflective of the diversity

of the HIV/AIDS sector itself. There were hugs that evening. There were tears. There was tension: *Would one of my opening speakers show up? So-and-so is triggered, how can I support them? Hello! It's been ages!! Oh wait, I forgot to put out the punch!* There was hope. Not a generalized sense of hope, but a specific one. There was hope in what these collectively-produced images and installations might do to shift someone's thinking when hung-up on an agency-wall. Not any wall. An *agency* wall.[6]

Engagement is always relational and temporal – an experience, that Ahmed (2014) might describe, as an experience of will, of reaching towards the "not yet".[7] As García Canclini (2014) argues: "There is no direct, mechanical line that goes from viewing a spectacle to understanding society and from there to a politics of change. In this zone of uncertainty, art is suited not so much for direct action as for suggesting the power of what hangs in suspense. Or of what has been left hanging" (pp. 170-171). This "indeterminacy" and "unpredictability of effects" that García Canclini (2014) refers to may be seen as at odds within the field of public health and the program science of scaled up interventions that so many community engagement initiatives are based in. In many ways, health requires the predictability of effects -- people's lives depend on it. Thus, if public health is the space to explore what has happened, or what we would like to happen, creative practice - my own or the collective experience of co-creating with participants - may be a ripe site to explore what has not yet happened (i.e., the possible, or the not yet).

[6] This signals to Ahmed's (2017) work on brick walls and other hard histories, where she speaks to the metaphor of the wall in institutional diversity work. Walls only come up when institutional change comes up.

[7] According to Ahmed (2014), "the will in this conceptual horizon is understood not as something a subject has, or experiences itself as having, but as what a subject develops, or must develop, to a greater or lesser extent, over time" (p. 61). She explains that ideas of will (good will, ill will) are bound up with ideas of morality, health and sexuality. I also see will as connected to engagement, through the will to participate.

I see this "not yet" in the installations and images produced by participants, as discussed in *New Directions for Photovoice*, but also indirectly in the future-oriented concept of journey. I see the "not yet" in the process of creating my mobile. It is perhaps not surprising that journey emerged so centrally in our study. When discussing *Journeying Together*, one of my co-authors helped me understand how the facilitated nature of the project created a space for participants to make sense of what was happening in his organization. Another one of my co-authors frequently describes journey as the "*unintended* outcome" of our project. Journey surprised us all. Furthermore, for those of us who participated in this project, the project became a 'stop' so-to-speak on our own journeys. It was also a 'stop' on mine. On the evening of our community launch and exhibit, we were all involved in reaching towards *a not yet*. The photos, report, panels, and installations *might* have an impact – this impact is always future-oriented, because it has not yet happened. The impact also does not reside *in* the images, but in the relationship between image, and viewer.

Engagement as a beyond is in contrast to seeing engagement as something simply done to a community to produce a particular outcome (as a means), or a fixed state of being (as an ends). Engagement as a beyond also moves practitioners away from a line of reasoning that suggests that individuals/communities might follow a linear trajectory of unengaged – to engaged with the right application, and right activities, or that there is a properly-designed engagement process that can be pre-figured from the start (i.e., a proper curriculum or a proper pedagogy as Britzman (1998) would argue). It is also in-line with what Tuck (2009) describes as desire-based research, a framework that inspired much of this work. As Tuck eloquently writes: "Desire, yes, accounts for the loss and despair, but also the hope, the visions, the wisdom of lived lives and communities. Desire is involved with the *not yet* and, at times, the *not anymore.* (p. 417)"

Engagement, if we draw back to the etymology, is also suggestive of a commitment, a shared promise, or a meeting (Merriam Webster, 2018). But, who are we meeting? And, to what are we committing? To the end goal of the project? To completing the objectives or meeting the terms of reference? Yes, sometimes. I also think it is more than that. I draw my hope for engagement processes from the projects that have shaped me, moved me, altered me. Projects such as this one. These have been projects where I have needed to wrestle with my conceptions of self, and to reconcile the different and sometimes competing interests of my own goals and those around me. Like my mobile, they are often projects where I have gotten tangled up. These are projects where I have had to show up to others *and* to myself. As Ahmed (2014) reminds us, "Life experiences involve multiple collisions with objects and others. It is through such collisions with others that I form a sense of myself as (more or less) apart from others, as well as a sense of the surfaces of my body" (p. 26). It is through such collisions, like the collisions between the octahedrons in my mobile, that we come together, to meet, or to work collectively on a project.

Rather than an end or a means, such a theoretical shift might allow us to see engagement as informed by relationships, as well as specific actions and relations between multiple actors and objects. This contrasts with highly bureaucratized and often sanitized versions of public engagement that presume participants come with different but equally important views that are ready to be shared and reconciled through engagement processes (Gregory & Lock, 2008). It also intervenes in the narratives espoused by participation typologies presented in chapter one.

As Ahmed (2000) asks: "*What are the conditions of possibility for us meeting in the here and now*?" (italics original, p. 145). The 'commitment to' and 'meeting with' in engagement might be conceived as a commitment to journeying together, or to the shared value of collaboration. It may also be a 'working through' to an unknown outcome. If we are to truly commit to working

together, we may not always know where we are going. Even if we have an end point, if a community engagement does what it is set-up to do (in theory), the end point ought to shift and morph over time. Like the puzzle Empower participants created and exhibited, engagement is often a process of grappling with how our pieces fit, or don't fit. It also involves trusting in an uncertain process.

Schulman (2006) differentiates between the terms participation, partnership and engagement in youth-adult partnerships. While focused on youth engagement, her work can be applied to community engagement in health, more broadly. For Schulman, participation comes *before* partnerships. She describes partnerships as *a part of* engagement. For Schulman, partnership is defined as a consistent, mutual relationship between partners with shared value. Here, shared value might be akin to my focus on shared commitments. Moving from here, she defines engagement affectively - as involving partnerships and participation: "when youth adult partnerships possess a feeling of *passion*, *excitement* and intense focus *emanating from a belief* and commitment to collective action (emphasis mine, p. 30)."

Unlike resistance, which as Tuck and Yang (2014) argue, does not require us to believe in it to work, engagement requires a suspension of belief – in the same way that a promise or commitment does. We know that promises can be broken, but we hold out hope for them nonetheless. In any collaborative project, when we are working on a common goal – even if differently understood – it is a project that has yet to be completed. And, just like in education, or health, there are no guarantees. This is why the harms of community engaged processes (e.g., tokenism, burn out, projects that are fully formed before community members arrive) can be felt so strongly. As my colleague and co-author, Kamliah Apong shared with me while writing our chapter *What's glitter got to do with it: Re-imagining harm reduction, decision-making and the politics of youth*

engagement, one can participate without one's consent (as with juvenile detention programs), but engagement requires active and ongoing consent (Switzer et al., 2016). If we understand engagement as involving active and ongoing consent, then engagement is *always* becoming, *always* contextual, *in and over time*. It can never be just an end or a means. It is composed of people on individual journeys. And the process itself, is also a journey.

Troubling the "we" in collaborative work

To draw on the work of Ahmed (2014, 2017), this study and the nested PhD dissertation was a difficult, bumpy journey. Over the last several years, there have been many nights of thought-wrestling over such bumps. Many of these bumps had to do with issues of power and collaboration. These issues are always inherent in qualitative research; however, I would argue that they are enhanced in collaborative, participatory work. Did I over-step, or over-ride a decision in a meeting or did we really come to it collectively? I continually questioned if my community co-investigators had enough information to make an informed decision, or adequately provide feedback on a piece of work, like some of our collaborative publications. The challenge with these reflections, of course, is that I don't always know. And, as someone who has devoted the bulk of her time and resources to this project, my reflections are most certainly partial.

Drawing again on the work of Ahmed (2004), there were many 'sticking' points in this work. Many of these sticking points required me diligently work through many of my own investments in the process. As Gaztambide-Fernández and Matute (2013) write, "Since pedagogy is always relational and driven by desires and intentions, the central question becomes whose desires and intentions are enacted and imposed pedagogically and to what end" (p. 59). I had two simultaneous desires that sometimes conflicted: to ensure this project led to organizational change, and for us to

do this work together. Sometimes these desires conjoined, and sometimes, they were incommensurable.

There were many 'sticking' points when navigating feedback, especially with community co-investigators who I frequently connected with for input, and sometimes co-design. I often wondered how power dynamics played out in these moments. Sometimes, it was necessary to pull the 'research design' card in order to protect the overall scientific integrity of a study. For example, one community investigator called me a few hours prior to a deadline, wanting to make changes to an abstract that we were submitting to a health conference for clinicians, and allied health professionals. I knew, if we made the suggested changes, it might negatively affect our review score. In this case, the feedback I received was not in-line with expectations for 'rigorous' academic research. I balanced this by figuring out ways to integrate the feedback into a co-led workshop we were conducting at the same conference. Since the workshop was already accepted (and had more time than a 10-minute oral), I knew we would have more flexibility over content. And yet, I wonder: is this enough?

The collaborative writing process was similarly sticky. When I am the one with the time and resources to commit to writing, are the collaboratively written chapters *really* polyvocal? When co-writing, *What's Glitter Got to Do with It: Re-imagining Harm Reduction, Youth Decision-Making and the Politics of Youth Engagement* (Switzer et al., 2016), myself and co-authors (eight youth researchers) spent six months, twelve meetings, and multiple one-on-one conversations co-writing a single chapter. In this case, the chapter was the project. In this project, our journal articles were one of many outputs, and resources needed to be balanced appropriately. And yet, I wonder, how accurate is it call them co-authored? Are the co-authored outputs an accurate reflection of their ideas, *our* ideas, or mine?

I sit with these tensions, and they tug at me. I could chalk up these complication to capacity-building and project design (i.e., how to write an abstract, how to balance time and resources), and yet, power is much more complicated. It is not always about the 'appropriate' feedback, and when or where one receives it. Or the 'right' project decisions. In this study, project decisions needed to be made daily and it was not always feasible to consult people. And, yet. And, yet. As a white, middle-class, stably-housed academic, there were many power dynamics at play. For example, in the particular case of the abstract, the feedback came on a Friday night at 9:30pm, a few hours before the cut-off for conference submission. I was not able to integrate any of it, but I wonder – had a professionally-trained academic called me late at night, would I have taken the feedback more seriously? Here, issues of race and class get particularly compounded when I think through who gets access to academic training.

Power also flowed-differentially. For example, at some of the sites, when it came to interviewing staff in management positions, these were individuals who had power over my career. Similarly, the research team was composed of much more senior researchers, including those who had supervised me in different capacities. Sometimes I had to push back in order to best represent the interests of participants or community co-investigators. For example, I had to support one of my co-investigators in advocating for the theme of non-participation, when several other team members initially dismissed it as not visually significant across the data-set.

Nonetheless, I was surprised by how often community co-investigators spoke up and sometimes challenged academics on the team (including myself) or offered feedback. In fact, their moments of challenge fundamentally changed the study. It was community co-investigators that so expertly helped me curate and advertise our community exhibition, and related participatory activities. It was community co-investigators that pushed me to look more at the impact of loss

and grief in the photos. I have a vivid memory during the development of our coding framework. One of my community co-investigators started categorizing the photos. I asked what he was doing and told me he was searching for the "spirit" behind the photos – which he went on to explain was loss. I have been long-fascinated by absence in photographs (Mitchell, 2011), however, I couldn't see this absence on my own.

Of course, even receiving feedback is complicated. I was once informed that harm reduction was not relevant at one of the sites, and should not be referenced (even though I knew that many participants used drugs). It was also not uncommon to receive feedback that we needed to bring something into our work that was not represented by the data, or more commonly, *only* represented at one-site (e.g., the importance of GIPA). For example, during a collaborative analysis meeting, one of my community co-investigators made a comment that we were *not* talking about treatment. From a research perspective, one cannot make issues of treatment a finding if the issue of treatment was not shared by participants. That being said, this comment helped me identify this absence as significant. Within the HIV sector, appeals for engagement are often made around improved health (e.g., a relationship between participation and reduced viral load, or medical adherence) (Genberg et al., 2016; Kenya, Chida, Symes, & Shor-Posner, 2011; Marino, Simoni, & Silverstein, 2007). Not one participant identified adherence to treatment in our study. If they chose to discuss the benefits of engagement, they spoke to the overall benefits, through impact of participating on relationships or their personal journey.

But perhaps this is not so surprising. To return to the concept of pedagogy and desire, (Gaztambide-Fernández & Matute, 2013), I went into this study with a desire to "push against" individual, behavior-based understandings of engagement. Engagement as a beyond (rather than means or an end) shifts our focus from seeing engagement as something 'done' to a community to

a relational act. This is in contrast to oft-cited understandings of engagement as something that produces a measurable effect or change within the self, as seen in claims that GIPA might produce lower viral counts. Thus, the comment about not talking about treatment was instructive. It helped me map my fingerprints, even in an outwardly-appearing collaborative process.

I find resonance with the work of Torre et al. (2008) who describe participatory action research as a "contact zone." Indeed, it is. Rather than seeing the purpose of this work as intending to resolve difference, Torre et al. (2008) use this metaphor to underscore the way subjects are "constituted in and by their relations to each other" (p.25). For example, it was often in these precise moments of navigating feedback or suggestions for future directions that I felt issues of power most affectively. I felt these moments affectively because it pushed up against the idea of who I was and my desires for collaboration. The reality was, as the one doing doctoral work nested within the project, I would be the one defending any findings or methodological decisions. The affective dimensions were also real. I was overly-invested in the project. I still am.

Ahmed's (2004) work on affective economies is useful here. She argues that feelings do not reside in subjects, but are produced as effects of circulation. Our different desires ricocheted with issues of power (our roles, but also social location), that that were enacted in the moment a conversation or decision felt 'sticky.' It was in the moment that I *chose* either consciously or sub-consciously to apply or push-back against a piece of feedback that my role as academic became entrenched. Feedback and ideas are selected and sorted – sometimes consciously, but often unconsciously by our affective investments. We subconsciously turn towards or away from an idea when excited. My excitement was often impacted by issues of scope, rigor, or timing. There was not enough hours or dollars for all the ideas and suggestions I received.

I often felt grateful for and simultaneously constrained by long-standing relationships I had with some participants, who had many ideas about how we could 'grow' the project. In some cases, sparked ideas were taken up outside of the formal project. This was the best-case scenario. However, in others, this wasn't possible. I was delighted participants took so much ownership over the project, but I needed to ensure the project was feasible. I could take all the community input but I also had to a role to play: to make sure we could complete the project within our budget, time-frame and to ensure that findings would have impact. At the same time, I worried what might happen if I couldn't take-up an idea. I wanted to stand behind my words: *we were going to do it together*! And yet, as Liebenberg (2018) argues, participatory research is about *combining* research and action to bring about social change: "Research teams need to consider the rigor of their findings, ensuring that they create a sound knowledge platform for which to advocate for change" (p.2). Balancing these two poles was often at the heart of this work. The simple truth is I needed my community co-investigators and participants more than they needed me. Working so closely with community members not only helped for recruitment and to ensure our project design was relevant, but also deeply enriched my theorizing. Every article in this dissertation was directly informed by a conversation that 'stuck' with me – a conversation on a panel, on the bus, or over a cup of coffee.

We must engage in these tensions if we are to move forward with the possibilities of engagement. These sticky moments - what Pillow (2003) calls as reflexivity of discomfort - are ones we don't often talk about when it comes to community engagement or CBPR. They are the "uncomfortable spaces generated by the irreconcilability and impossibilities these reflections raise" (Sandlin, Szkupinski Quiroga, & Hammerand, 2018, p. 59). Just as there is no solidarity

work without difference (Gaztambide-Fernández, 2012),[8] engagement must also be conceptualized, in direct relationship with difference and ideas of incommensurable interdependency. As Gaztambide-Fernández (2009) argues, "We invest a great deal of personal meaning in the discourses we engage, the spaces we inhabit, and the person we are convinced we are. […] If we are to engage in curriculum work that has significance, we have to be willing to put a lot of who we are – or rather – who we believe ourselves to be – at stake" (p.34).

Here, a working through difference does not suggest an easy resolution (as to work through a problem, to seek a resolution) but rather, to stay in the muck of it all. As Butler (2005) reminds us, staying in the 'muck' of has many generative possibilities:

> We must recognize that ethics requires us to risk ourselves precisely at the moment of unknowingness, when what forms us diverges from what lies before us, when our willingness to come undone in relation to others constitutes our chance of becoming human. To be undone in relation to others is a primary necessity, an anguish to be sure, but also a chance – to be addressed, claimed, bound to what is not me, but also to be moved, to be prompted to act, to address myself elsewhere, and so to vacate the self-sufficient *I* as a kind of possession (p.136)

Thinking through our investments in engagement processes, and grasping at the limits of our knowledge may be a long, but worthwhile process. However, we owe it to ourselves, and our participants to do this work.

Strengths and limitations

This dissertation contributes to multiple disciplines and fields: public health; education; participatory visual methods; and community-based participatory research. Across these disciplines and fields, scholars and practitioners are often grappling with this 'thing' we call

[8] Gaztambide-Fernández (2012) argues that all projects of solidarity operate within the dynamics of colonialism, in that they always operate in tension with the logics of domination. Engagement, similarly, operates within similar tensions, and promises.

community engagement. As explored throughout, despite the ubiquity of the term, there is a lack of theoretical work conceptualizing this term and practice. As Snoeren, Niessen, and Abma (2012) explain, when it comes to community engagement most studies focus on the role of participants, and eclipse the role of the researcher. This is problematic as often the values or intentions of researchers or practitioners can ensnare participatory processes. My work builds on this call and presents a variety of ways in which scholars may explore issues of engagement (figure 1). I also provide re-conceptualization of engagement as not a means, or an end, but a beyond.

Methodologically, my work contributes to participatory visual methods literature by troubling the role of the image in photovoice and expanding on the range of possibilities for photovoice exhibitions. This study provides also provides a blended model for doing photovoice alongside a CBPR approach. While there are some exceptions (Castleden, Garvin, & Huu-ay-aht First Nation, 2008), this is an area that is often not addressed in photovoice literature, despite the theoretical and methodological linkages (Evans-Agnew & Rosemberg, 2016; Liebenberg, 2018). Additionally, the use of installation in photovoice is a previously unexplored direction which may challenge realist or "docu-photo" approaches to photovoice as a method.

The impacts of the larger study, within which this dissertation is nested, also has many contributions. Together, we created several "provocative products" (Fine & Torre, 2008): 67 photographs for exhibition (organized thematically); 3 installations; a community report; a website; and multiple workshops, panels, and presentations that shared findings outside of traditional academic spaces. These products have travelled to different organizational and conference sites and been viewed by different audiences. Fine and Torre (2008) argue that

participatory researchers must work with, and alongside communities to co-develop more "provocative products" in our current political climate.[9] They argue:

> researchers have a responsibility to think through, and have at times, find *audiences of worth* – those who deserve to hear, who will respect and engage the brilliance and passion of youth researchers. We speak here of audiences open to new and different knowledge that may destabilize what has become comfortable, audiences willing to cross institutional lines, audiences willing to be moved to action – full bodied, not just in the mind (p. 11-12).

I have been astounded by the community-uptake of this work. We first shared our work at our community exhibit and report launch in Dec. 2017 to over 100 community members, service providers, policy makers, and organizational decision-makers. It was in this space, that we distributed copies of our community report. At this event, a panel of community-investigators spoke eloquently about their involvement in the project and offered up recommendations to audience members. Since the launch, we have been asked to exhibit our collection of photographs and installations at a number of community events. We have been invited to lead a number of community workshops and panels about our work together in a variety of conferences and forums for: people living with HIV and service providers (Opening Doors); harm reduction service providers (the Ontario Harm Reduction Distribution Program); and youth and adult allies (Wisdom2Action Youth Forum and Youth Sexual Health Symposium - a conference on youth sexual health). We also facilitated a workshop at a provincial HIV conference for clinicians, medical residents, researchers and community members. At one of these forums, the organizers were so interested in our community report that they funded a new print run of 200 copies so that each of their delegates could receive a copy. Our website (featuring an online exhibit and our

[9] While Fine and Torre are speaking to youth participatory action researchers, I take up their call more broadly.

report) has been distributed to over 3000 service providers and community members nationally through a national HIV knowledge broker organization.[10]

On a more micro level, the project has also led to impact at the partner organizations. For example, a staff member from one of the organizations shared that the project led to significant conversations during their strategic plan, and influenced the development of a new leadership program for people living with HIV. At another organization, the exhibit – which was up for 3 weeks – became an important talking point between clients, volunteers and staff. One of the community co-investigators informed me that each day he went in for lunch, he sat in a different area of the cafeteria (where the exhibit was displayed) to host conversations with other clients about the photographs. I was also informed that the exhibition became a 'stopping point' on a tour for hospital volunteers during their training. At another site, participants have told me the project has inspired them to start some of their own projects.

Despite many of the strengths, there are several limitations to this study. Many of these limitations are addressed in each of the manuscripts and are not repeated here. However, there are a few limitations not identified throughout. First, the number of sites and the methods employed resulted in a large amount of data. The issue of data overload has been reported by other qualitative scholars, and is not unique to this study. Implementing this photovoice study at three sites provided a rich opportunity to look *across* sites, and identify the contextually-specific dimensions of engagement work. However, this prevented me from going in-depth at any one-site. The sheer number of sites also meant that recruitment processes needed to be speedy to meet timelines. At each site, study spots filled up quickly. However, had we spaced recruitment over a longer period

[10] https://pictureparticipation.wixsite.com/gallery

of time, we may have been able to includes individuals who were less involved in the organizations at the time of recruitment.

For example, at one of our public panels, a woman in the audience stood up and explained that she felt excluded from our study because when she went to 'sign-up' she was told it was full. She explained that as a trans woman who commonly experienced social exclusion, the experience of being told she could not participate was particularly difficult. I had never met nor spoke to this woman prior to this moment. Our study was a limited to a fixed number of participants due to resources, scope, and design (i.e., a study with a larger sample would have had a different design). Had she inquired during the recruitment period I would have been delighted to have her participate. Nonetheless, this moment speaks to some of the unintentional harms that we can cause when doing this research. Here, what might seem like a textbook issue of breadth versus depth of participation (we chose depth over breadth) comes up against the very real vulnerabilities and processes of social exclusion many people I work with face.

The small sample size also created issues for confidentiality especially with staff participants who spoke from their vantage point as a staff-member in a particular role. To mitigate this, I had upfront conversations with individuals about these risks moving into the study. What I did not anticipate however, was how the small sample size (of all participants) would affect the treatment of demographic data. In this study, I conducted an open-ended demographic survey over the phone with individuals to ask them how they self-identified under a number of axes (e.g., race, indigeneity, housing status, drug use experience, serostatus). I explained that because some of this was sensitive information nothing would be linked to them specifically, and that the information would be used to present narrative descriptions of who was in the study, and at each site. However, this meant that when it came to applying an intersectional analysis, my hands were tied. Unless

participants self-identified in their speech or in their written narratives, I was not able to use any of the demographic information they had provided. This was further compounded by the fact that sometimes participants held prominent roles in the community, wanted to be credited, and that as a CBPR project done in partnership with community-based organizations, confidentiality could be very easily compromised.

Nonetheless, even if I was able to link this information directly to participants (e.g., in the case of a larger sample size), there are considerable challenges with identity-based surveys. Identity is a complex phenomenon. Although I explained to participants that they were able to self-identify, for some, these identity markers were complicated. Some chose not to answer certain questions (e.g., sexual orientation); some identities changed over the study (including identities that are often presented as fixed, like race); and in some cases, how participants self-identified 'on the record' conflicted with how I perceived or experienced them in other moments. Participants might present themselves in one way on one day, and have it change on another. I see this incongruency as reflective of the way in which identities are never stable, and often shifting (Alcoff, 2005; Day, 2014). This is further augmented in the case of stigmatized identities such as mental health or drug use. These shifts were highlighted by my research design (multiple encounters over time) but also pre-existing relationships with some participants.

Last, the group-oriented nature of the photovoice process allowed us to collectively construct ideas about engagement (and determine how to best share them – e.g., installations). However, this may have largely attracted individuals who were drawn to more extroverted means of participation. Similarly, while I encouraged participants to attend if they were no longer involved in organizations, in all cases, I received interest from individuals actively involved at the organization at that moment of time. Had I consulted only with participants who were not involved

(which would have required a different study design) we likely would have had a different set of findings. That being said, it is difficult to logistically connect with participants who are not "engaged" on a study about engagement.

For example, at the hospital site, due to major organizational changes happening at the time of the study, we were not able to host our final workshop until two months after participant interviews. This meant that the first four workshops and interviews were held in the old building. The fifth workshop was held in the hospital's new space. While our numbers for previous workshops were high, our numbers for this workshop were low. Anecdotally, I heard that the organization was struggling to get clients in the door after the building transition. Nonetheless, I wonder what missing voices might have contributed to this discussion.

Participants may have also been less likely to disclose criticisms or challenges with organizations in a group setting – especially where they are currently involved in potential leadership roles. I was surprised by how few critiques I heard, even when prompted. This may have been because people were worried that critiques may make their way outside the room, or be taken up negatively by others. Of course, this did not mean participants always presented a positive view. As discussed in *Youth Talk Back*, participants chose to air their critiques of (youth) engagement by speaking outside the organizational context. Participants at other sites did share critiques, however, not as many as I expected. Since the lack of critique was an issue across all sites – including sites where photos were discussed by interview - this suggests that other factors (e.g., organizational focus, or the group element) may have influenced a perhaps, over-celebratory approach. The workshops at each site were also organized in different configurations in relation to power dynamics between institutional roles. I met with staff and community team-representatives to design the workshops. I asked them who should be in the room, and where we

should hold them. These conversations informed our design. For example, where there were clear power differentials in terms of roles, as in our clinical site, we divided participants. At other sites, where there was more role fluidity, we met as a single group.

Nonetheless, who is in a room, or where a focus group is held will always affect what people may choose to share in any given moment. Most likely, because of my relationships with each of the sites, or because workshops happened inside the physical sites (even if requested), participants may have seen me, and the project as an extension of the organization and been reluctant to offer critical views. (It is also possible that these critiques may have been more coded, and that with distance, I might see them in a different light). This suggests that studies looking to explore challenges of engagement organizationally may not wish to take a case study approach, nor one that relies on group-oriented methods. If there were more resources, one might consider doing an interview with each participant to accommodate this challenge. In the cases where I conducted photo-elicited interviews, I was able to probe more, ask follow-up questions, and received more critical feedback. However, extra interviews would have resulted in participant fatigue (i.e., asking too much of people) and as discussed above, data overload.

Future directions for research

This dissertation focused on how stakeholders conceptualize engagement within and across HIV community-based organizations providing programming, service provision, or care. As part of this conceptualization, I put forward the concept of engagement as relational (and thus ethical and affective), dynamic and pedagogical. Future areas of research might focus in on any one of these components – in particular, the relational, ethical or pedagogical components of engagement. For example, I am particularly interested in exploring, in greater detail, the pedagogy of engagement in community-contexts. How do practitioners facilitating community-engaged

projects conceptualize their pedagogical work? In other words, what happens once we bring stakeholders into a room, and we meet across a table? Although facilitation has been identified as an underlying successful factor in successful community engagement projects (Head, 2007), it is only ever casually referenced, suggesting that in-depth analysis of the role of pedagogy in community engagement might warrant further study.

For example, in her work on advisory committees with people who use drugs, Belle-Isle (2016) found that structural supports (i.e., compensation and other supports), solid relationships fostered on trust, relational and reflective dialogue, and well-facilitated meetings were critical elements in allowing community members to feel as if they could contribute to shared decision-making on community advisory committees. Similarly, Boivin, Lehoux, Burgers, and Grol (2014) did a randomized control trial which assessed what they called the "key ingredients" for successful public involvement in health care policy. They determined that legitimacy and credibility of participants' arguments (often gained through lived experience; careful preparation meetings; and the ability to speak 'on behalf' of a community – however contested); a supportive context; recruitment (who is at the table); and careful moderation (i.e., facilitation) all operated in tandem to create the necessary conditions for 'successful' community involvement in policy change. However, unlike Belle-Isle (2016), this study did not attend to issues of power – beyond that of professional/community divides.[11] I am particularly interested in studying pedagogy with an attention to social and structural relations of power.

[11] Gender, class, health and socioeconomic status are casually mentioned in this paper. There is no reference to race, sexual orientation, or stigmatized identities – such as drug use experience, HCV, HIV status, sex work, etc.

Many of the seven key study themes could be further explored. As many of us continue to mourn the lives of those lost in the overdose epidemic, how do organizations and individuals attend to engagement in the context of ongoing grief and loss? I have been profoundly struck by the overlap between the HIV epidemic (and the stories gifted to me by long-term survivors of HIV) and the current overdose epidemic. The backdrop of grief and loss has a profound impact on designing and leading peer-led programs and services, especially in the harm reduction sector.

Concluding Remarks

How might we think through the pitfalls *and* promises of engagement work? Community engagement may at best – fall short of lofty aims – and at worst, cause harm if we do not think carefully and critically about what we are doing, and why. Merely 'thinking through' these issues may also not get us out of these traps. I have caused harm. We all have. And yet, as I have learned from many of the communities I have worked with, the energy in a room when collectively working on a [political] project is profound – not because what happens in an engaged-process is some sort of transformative black box, but because we are in the process of creating something new: new networks, new relationships, new ideas, and sometimes, new visions for how we want the world to be. As Tuck and Yang (2011) argue, " non-teleological theories of resistance are messy and the end game of such resistance is unfixed and always taking shape" (p. 522).

Such a vision stands in stark contrast to the world of measurement and certainty often advocated for within the field of health. Imagine the outcomes, if we let go of outcomes! As Gaztambide-Fernández (2012) asks (when teasing out the opportunities and tensions of solidarity work): "What imagined and unimaginable outcomes might become available if we were willing to risk the possibility that we simply do not know where we are going?" (p. 55). This harkens to the

beyond of engagement work, which as discussed in this dissertation, is also invested with working across differently socially-situated communities.

I am intrigued by conceptions of engagement which allow us to think through how different people come together to collectively co-create, and in doing so, not only create new ways of thinking, but new ways of being together. While we may never get outside of the logics of domination, or the potential harms that community engagement projects may engender, theoretical shifts in understanding engagement may open up new conditions of possibility. If attuned to its relational features, community engagement can be profoundly productive. As practitioners engaged in work of deconstructing binaries between expert and 'client', in democratizing knowledge production, in trying to shift power relations, we are trying to create new worlds and ways of producing knowledge. If one was to ask, 'what is this knowledge for?' this is where the answer would land.

If this work has taught me anything, it is that there is no binary between resistance and reproduction (Tuck, 2009; Tuck & Yang, 2011). This work is messy. And yet, I must step forward all the same (Salverson, 2006). To end on the words of oft-cited Ahmed (2014), "We have to enact the world we are aiming for: Nothing less will do" (p. 170). No single program, curriculum, intervention, or research project - however lofty and well-designed - can fully intervene in the context of structural inequities. However, as my participants have taught me, there is hope in engagement – even if complicated and complicit. There is hope in finding and creating the cracks in dominant engagement discourses, but only if those of us in positions of decision-making power take the lead from those living with and affected by issues in order to find the cracks, and collectively widen them.

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Appendixes

Picturing Participation:
Understanding Engagement in HIV Programming, Service Provision and Care

Who are we?

We are a group of researchers from York University, Concordia University, Windsor University and University of Toronto who have partnered with service providers and program managers from Casey House, Toronto People With AIDS Foundation (PWA) and Queen West – Central Toronto Community Health Centre's Empower program. This study is funded by the Canadian Foundation for AIDS Research (CANFAR), with support from Reach 2.0 and the Faculty of Environmental Studies at York..

What are we doing together?

We are doing a research study to learn about how people with different roles in HIV organizations or programs understand the idea of *engagement*. This means learning more about the successes and challenges of meaningfully including people living with, and affected by HIV (PLHIV) in HIV programming, services and care. For Casey House, this might mean looking at client engagement. For Empower, this might mean looking youth engagement. For PWA, this might mean looking at volunteer engagement.

What will <u>you</u> be asked to do?

You are invited to participate in five 2-3 hour photography workshops. If you are at Casey House, you will participate in one interview, and four workshops (if you are a client), and one interview and two workshops (if you are a staff).

At these workshops, you will learn tips about picture-taking and be given some guidelines (aka 'rules to follow' when taking pictures for our project). **You will be given a camera and asked to take photos about the engagement of people living with or affected by HIV at Empower, Casey House or PWA.** You will be provided with lots of support and training. You will then be asked to share (e.g., talk and/or write) about some of your pictures. You may also help with finding key themes by looking and talking about other people's pictures. With your permission, we will be photographing and audio-recording our sessions, and may ask you to fill out an evaluation form. In select cases, if you are not able to participate in the workshops, we may ask to interview you individually to discuss your photos.

At the end, we may create an exhibition and a video. You get to decide which pictures (if any) you want to publicly share.

Who will be in these workshops?

We are interested in hearing from different stakeholders (clients, participants, volunteers, clinicians and coordinators) about their understandings of engagement. At Empower, this may mean participants, mentors, and coordinators may participate. At PWA, this may mean volunteers, and staff may participate. At Casey House, there will be separate workshops for clients and staff. At the last Casey House workshop, there will be clients, staff and clinicians in the workshop together. We'll talk about what this means in advance so you feel as comfortable as possible. We expect approximately 9-10 participants at each site. During the workshops there may also be co-investigators, research assistants, and an artist-facilitator. We'll introduce everyone in the room and clearly explain our roles.

What will we do with the photographs and information gathered?

We will review the photographs, writing you produce, and recordings of the discussions we have together, to help us better understand how to meaningfully include people living with and affected by HIV programming, service delivery or care. In order to provide a larger understanding of who participated in this study, we will also use the information you provided in the demographic questionnaire. However, this information will not be linked to you. We will share our findings in a report, education and training materials, in a video, in a public exhibition, at conference presentations, in journal articles and in Sarah Switzer's PhD dissertation.

Anything you make in these sessions belongs to you. We may ask your permission to use your materials (e.g. pictures or drawings) in presentations or events. You will get to choose which photos (if any) of yours you would like included, and you don't have to share if you don't want to.

Are there risk & benefits?

We understand that personal issues can come up at any time, particularly when talking about our experiences accessing or participating in HIV services and programs. There may be other people in the workshop that you don't want to share in front of (i.e., your peers, a coordinator or staff member, clinician, etc.). There is always the chance someone may become upset, frustrated, or embarrassed while participating in the research, or that something might happen that we don't expect. Should you need additional support, we will link you to support staff at each agency that have the clinical skills / training to connect you to the most appropriate services.

We will try to create as safe and supportive a space as possible by creating group guidelines and doing our best to stick to them. We will also create opportunities for people to share individually and/or in groups. The goal with these workshops is to benefit the HIV sector as a whole by learning more about engagement. We hope individuals who participate also benefit from the experience by findings new ways of expressing themselves.

What about confidentiality?

The project team will protect confidentiality to the extent permitted by the law, and individual responses and/or photos will not be linked to you -- unless you want them to be. However, during the workshops it can be difficult to assure confidentiality from everyone. We will ask everyone present not to repeat what is said during these sessions after they leave. But, we cannot guarantee this.

Some of the people participating in these workshops are also on the research team, and will be helping us analyze the data (i.e., photographs, recordings). However, your names or identifying information will be removed from the transcripts and photos before sharing (unless you tell us otherwise). Basically, we don't

share anything you say in the workshop or interviews without your consent (like your name linked to a recording of something you did). Members of the research team will also be signing a confidentiality agreement.

What if I want to be named or show my face?

If you want to be recognized for something you produce as part of this project, or have your face shown, you can. However, you do not have to. There will be plenty of ways to participate without being named or shown.

What does this have to do with my medical care, services, or participation in programs at Casey House, Empower, PWA or any of the universities involved?

Nothing! This research project is completely separate from the care or services you are receiving and will not impact your ability to access or participate in any of the services or programs at any of the participating organizations. Your decision not to volunteer will not influence the nature of your relationship with any of us either now, or in the future. If you are a staff member, it will not influence your employment at the agency.

What if I want to withdraw or stop participating?

This research is completely voluntary. This means you can stop, take a break, or leave at any time and do not have to provide a reason. If you decide you want to withdraw from the project, we will do our best to make sure not to include thoughts that may be captured on group audio file. Sometimes it can be hard to remove individual voices from a group recording, but we will try. We will not use any of your pictures without explicit permission.

Will there be funds to support my ability to attend?

Yes, we will provide food, honoraria, TTC tokens, and all of the supplies necessary to participate, including a camera. If you are a staff member of an organization, you won't receive honorarium, but we'd like to give you a gift card as a thank you.

If I have any questions or concerns about the project, you can contact any of the following:

<table>
<tr><td>Sarah Switzer*
Doctoral Candidate</td><td>Research Coordinator
York University</td><td rowspan="6">[contact information]</td></tr>
<tr><td>Sarah Flicker,*
Associate Professor</td><td>York University</td></tr>
<tr><td>Alex McClelland,*
Doctoral Candidate</td><td>Concordia University</td></tr>
<tr><td>Soo Chan Carusone*
Research Lead</td><td>Casey House Lead</td></tr>
<tr><td>Suzanne Paddock
Director of Programs and Services</td><td>PWA Lead</td></tr>
<tr><td>Kamilah Apong</td><td>Empower Lead</td></tr>
<tr><td></td><td colspan="2">People designated with an (*) are all co-principal investigators. This is another way of saying lead researchers.</td></tr>
</table>

This research has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in this study, please contact the the Sr. Manager & Policy Advisor for the Office of Research Ethics Office of Research Ethics, 5th floor, Kaneff Tower, York University at (416)-736-5914 at ore@yorku.ca

If you consent to the above, and would like to be involved in these workshops, please sign below. You may have a copy of this consent form.

Participant

Print name: _____ Signature: _____

Date: _____

Witness

Print name: _____ Signature: _____

Date: _____

Sample Workshop Agendas

Each workshop was locally modified to attend to logistical issues, or accessibility needs and/or interests. Sample agendas are presented as an approximate guide for our workshops. They show the range of ways in which we prompted discussions. Agendas were also used for workshop planning between my co-facilitator, research assistants, and in some cases, community co-investigators who helped with overall workshop design, or selected parts of workshops.

In most cases, activities were co-facilitated by myself, and a community-based research assistant, who was affiliated with Empower. Sometimes, student research assistants also supported with activities.

Agenda: Workshop 1 (Youth Site)

February 8, 2016, 5:00-7:30

Supplies/set-up:

- Food
- Honorarium Form, Honorarium, Tokens
- Workshop dates handout + consent form x 24
- Flip chart paper and markers
- Objects for icebreaker, Smarties, Smarties icebreaker handout

Workshop Aim: This session will include consent, an icebreaker and project orientation. We will also facilitate (a series of) arts-based brainstorming activities to think through ideas about engagement.

1) **Let's eat!**

2) **Introductions and brief check-in**
   - Name, pronoun, role in Empower, and how you're doing

3) **Informed Consent & Project Overview**

4) **Establishing our terms: Group Guidelines**

Turn on the tape

5) **Smarties Icebreaker**

   1) Take some smarties from the bowl. You can take as many as you want.
   2) Colours represent certain questions. Look at your smarties, and answer the corresponding questions on the handout.
      - *Red* - Looking back, what art mediums or activities have you used in your Empower workshop(s)?
      - *Yellow* - Tell us about your photo-taking experience (e.g., instagram, facebook, new to taking photos, creative photos, etc.)
      - *Brown* - What makes a space 'safe(r)' or more accessible for you?
      - *Green* - If you were a cartoon, book, or movie character who would you be?
      - *Yellow* - If you were the mayor of Toronto for one day, what would you do?
      - *Pink* - When you hear the word "youth engagement" what word(s) come to mind?
      - *Purple* – Wild card - tell us something surprising about yourself

6) **Break**

7) **Working with Objects**

PROMPT: Select one object that represents youth engagement in HIV prevention.

SHARE: Go around the circle.

DEBRIEF:

- What are the objects we see on the table? What were some of the things we heard?
- What was your process like for selecting an object?
- What were the connections / similar themes between people's responses?
- Any thing missing from our conversation?
- Anything that you learned from selecting an object that you might carry forward into this project (i.e., your photos, etc.)?

8) Check out, honorarium and tokens

Agenda: Workshop 2 (ASO)

May 19, 2017, 2:00-4:30

Supplies/set-up:

- Field notes and photos
- Honorarium Form, Honorarium, Tokens
- Cameras, batteries, SD card + SD reader + Camera form
- Scavenger hunt and prompt questions
- Visual Kit of images

AIM: Basic photography skills training and discussion about ethical issues when taking photos. Participants will begin taking photos, and also take photos in between workshops

1) **Agenda, Review Guidelines, Intros, Check-in**

2) **Photo Training: Photo Basics**
   What's in an image? : Visual Activity
   - Select an image from the table that you're attracted to
   - What do you like about this image? → Brainstorm on flip chart
   - Brief power point - photo taking tips

3) **Hand out Cameras - camera demo**
   a. Batteries, SD card, on/off
   b. Flash
   c. Camera Settings
   d. Timer

4) **Break**

5) **Photo Role Play (Can I take your photo?)**
   - Role play consent
   - Q and A

6) **Photo scavenger hunt**
   - Work in groups of 3
   - Debrief - anonymity strategies

7) **Check - out (with our bodies), honorarium and tokens**

Agenda: Workshop 3 (Hospital)

April 12, 2017, 1:30-4:0-0

Supplies/set-up:

- Guidelines - flip chart + computer
- Honorarium Form, Honorarium, Tokens
- X 2 Camera, batteries, SD card
- Extra: Can I take your photo forms?
- Instructions with Prompt Questions

AIM: Trouble-shooting. Participants will check in about their photo taking process

1) **Let's eat!**

2) **Check-in, intro and group guidelines**
   - Question: How did your photo taking go?
   - Trouble-shooting

3) **Brainstorm**
   - Re-orient people to research project.
   - Brainstorm: What does engagement mean to you?

4) **Instructions**
   - Go over photo-prompt handout and instructions - with help from community co-investigator

5) **Photo-Taking** (combined with break)

6) **Discussion**
   - How did that go? What was difficult? What was easy? Any unexpected surprises?
   - If time: Share out 1 or 2 photos from the group with focus group guide

7) **Check out and Next Steps**
   - Interview process for photo-elicited interviews and sign-up
   - Honorarium and tokens

Agenda: Workshop 4 (ASO)

June 2, 2016, 2:00-4:30

Supplies/set-up:

- Food; Transfer photos as people arrive and start eating
- Group Guidelines flip chart
- Computer x 2 + projector +SD reader
- Honorarium Form, Honorarium, Tokens
- Focus Group Questions
- Paper and pens for narratives

AIM: We will facilitate discussions with participants to discuss photos.

1) **Let's eat!**

2) **Check-in**

3) **Icebreaker: Soundscape**
   - Ask people to find a spot around the room, get comfortable, and close their eyes. When they are ready, vocally repeat a sound you hear.
   - Create a soundscape. It will be organic, and in concert.
   - Debrief experiential connections: working together, active listening, improvisation. Ask participants to link to how they understand engagement.

4) **Photo Transfer Cont'd**
   - Finish transferring remaining photos
   - Others: Begin to work on your narrative

5) **Focus Group**
   - Divide into two groups to be co-facilitated. One research assistant per group for time-keeping

6) **Break**

7) **Brief Group Discussion**
   - How did that go?
   - What were some of the discussions you shared?
   - Did anything surprise you?
   - What was it like hearing other people interpret your photo?

8) **Narrative Writing**

9) **'Partnered stretch' check out and honorarium**
   - Join a partner (ask for consent); link arms and stretch - when in your stretch, one word with how you're feeling

FOCUS GROUP GUIDE (EMPOWER)

Setting up the space:
Prior to starting the focus group, remind participants of:

- Group guidelines. We want to share the space.
- Purpose of the research
- For discussion of photos: We're not 'guessing' the meaning behind photos. We want to bring it back to our own experiences.
- Process of questions (audience (other participants) will respond first; then artist/producer; then both)
- Note-takers and timers in the room
- Check audio recording equipment

Question *** questions in italics are sub-prompts to be used only if needed*	**Who Answers**
1. What do you see in this photo? a. *Describe the parts of the image. What colours, objects, places, etc. do you see?* b. *Where is your eye drawn and why?* c. *What do you like about the photo? (You might reference some of the techniques we discussed in our second workshop)*	Audience
2. What do you think is happening (or going on) in this photo?	Audience
3. What does this picture tell us about youth engagement in youth HIV prevention programming? a. *What might the different elements of the image represent?*	Audience
4. Why did you take this photo? What does this picture say about how <u>you</u> think about (youth) engagement?	Participant
5. How does the photo (or _____ expressed by your photo) connect to your experiences? 6. How does this photograph connect to youth engagement at Empower?	Participant
7. How does this connect to your experiences?	Audience
8. Why do you think _____ might exist/happen? *Note: The goal is to probe deeper about an issue that comes up, and its connection to larger structural, or organizational issues. This question will likely be adapted based on content of discussion.*	Ask participant first; audience second
9. What is missing in the photo? a. *Are there things you wanted to capture but could not?* b. *What is outside of the photo frame?*	Participant
10. If relevant: Would you make any changes to the photo after hearing people's responses? If so, what would they be?	Participant

Agenda: Workshop 5 (Hospital)

July 12, 2017, 1:00 - 3:30

Supplies/set-up:

- Candle
- Group Guidelines from client workshops
- Honorarium Form, Honorarium/Gift Cards, Tokens,
- Printed package of narratives and photos for group analysis
- Sticky notes for group analysis + markers/paper
- 4x10 Printed photos – x 2: participant copy; workshop copy
- 8x10 - exhibit photos and narratives for display
- Mini note-pads

AIM: We will come together as a group (staff and clients) to look at themes across photos and celebrate our accomplishments.

1) **Let's eat!**

2) **Images and narratives** up in the space (with participant-chosen pseudonyms) to review as they come in.

3) **Welcome and Grounding the Space + review agenda**
   - Moment of silence
   - Centering group guidelines set by clients
   - Brief check in - name, and one thing you're looking to get out of today's workshop

4) **Icebreaker: Celebrating our images**
   - Place participants' (unnamed) photos on the table
   - To help familiarize people with the exercise, make connection to exercise (week 2). This time we will celebrate all the amazing photos that the group took.
   - Select a photo on the table (that you did not take), that you connect to in some way. Share why.

5) **Preface for Gallery Walk (Reviewing Our Narratives)**
   - Reflect on: What does it feel like to have your photos displayed with your chosen name on the wall?
   - Do you want to make any changes?

6) **Group Photo Analysis**

STEP ONE: Gallery Walk

   - Walk around and view and read images - small note pads available if needed
   - Encourage to participants to think about (Post on flip chart)
     - What stands out as similar?

        - What is different?
        - What surprises you?

STEP TWO: Preparing for our exhibit -- small group discussion

- Groups - groups of 3-4
- Note-taker in each group (research assistant)
    - Small group discussion:
        - What stands out as similar?
        - What is different?
        - What surprises you?

- Distribute photos/narratives package
- Groups to organize either by similar images or by narrative with sticky-notes
    - Strategy if people are stuck: What 3 things do all these photos have in common?

STEP THREE: Group report back (audio-record). Save sticky-notes.

7) Next Steps and closing

- How do you want to exhibit these photos?
    - Mini exhibit 'working group' to meet in the fall to help display these photos
    - World AIDS Day community exhibition

- Head, Heart, Hands Activity
    - With sticky/notes + flip chart + research assistants to transfer notes for people with physical access needs
    - It's been a journey! Reflecting on the past few months, what is one feeling you are taking with you?
    - What is one thing you think that you learned? (i.e., a skill, something about yourself, a realization, etc.)
    - What's next? What is one action you will take away? (A new spot to take photos, for staff, it might be a commitment, a question you're going to ask, something you feel passionate about fighting for, etc.)

- Honorariums/tokens

Instructions and prompts

The instruction handout was modified for each site, including site description, sub-prompts, and icons. The language was also adapted, based on in-depth conversations with community co-investigators. The instructions and sub-prompts were reviewed by our larger research team and then refined by myself, and community co-investigators, after the second workshop at each site. This allowed us to further tailor sub-prompts to the conversations we were having.

Instructions were provided to participants at workshop three. Prior to distributing this handout, we always started with a brainstorm to hear from participants first.

Sample Photo Instructions (ASO)

PWA is a partner in this photovoice project. We want to learn about how people understand engagement in different organizations providing HIV programming, service provision or care. Engagement has many different definitions, but often refers to including people affected by an issue in making-decisions or running programs. Sometimes it can also mean being involved, or participating in something.

At PWA, this might mean what it means to volunteer in the Dreaming and Opportunities program; be involved in committees; or work as a peer worker. It might also refer to what it means to be involved in a volunteer-led program or in research.

In some of the organizations involved in this project, engagement is talked about as:

- *GIPA or MIPA - the greater or meaningful involvement of people living with HIV*
- *Nothing about us without us - involvement of people who use substances in program/policy change*
- *Volunteer engagement*
- For youth by youth or peer education
- Client engagement
- Youth engagement

For some people, these terms or ideas can be confusing, unclear or not feel relevant. For some people, these terms or ideas are important.

What does "volunteer/peer engagement" at PWA to you <u>personally</u>? What does it look like in practice at PWA?

Take a photo (or a series of photos) to help represent your ideas. **You can take as many photos as you want, but you may only have time to talk about two of these photos as a group. ** We will help you brainstorm different ways of approaching this task, and there's lots of support if you want it.

You have **creative freedom** in how you take the photos. There is no way to do this wrong!

Please do <u>not</u> take any photos of other clients accessing services PWA. If you decide to take photos of other people (i.e., other volunteers, staff, people outside of PWA), please remember to explain the purpose of the project like we practiced during our workshop. You do not have to put yourself in the photo if you don't want to.

If you have questions please ask!

To help get you thinking about your photos …

These questions are here in case you need some help brainstorming what photos to take. They are totally optional. **You can answer one of them, all of them, or none of them**.

	Photo Prompt (i.e., question to consider)	✓
1	Take a photo that shows a unique perspective you bring to PWA. This could be from your experience, your identity, or an idea you have.	
2	Take a photo that represents a memory you might have of being involved as a volunteer, or peer worker in your role as _____.	
3	What makes engagement (i.e, GIPA / MEPA) difficult PWA? Take a picture to show us what is not working or what is challenging.	
4	If you could run PWA for a day, what would you do? How might you involve clients, volunteers or peer workers in developing programs or making decisions? Take a photo to represent some of your ideas.	
5	Take a photo that represents how volunteering or working at PWA as a person living with HIV has *impacted you*, or how you have *impacted PWA*	
6	Select an item from the list below that is important to you. These ideas were expressed by you in our first workshop. Take a photo (or a series of photos) that shows why this is important when thinking about volunteer or peer engagement at PWA: ➢ Health, wellbeing and holistic engagement ➢ New connections or relationships with volunteers, clients or staff ➢ Stigma ➢ GIPA/MIPA ➢ Dreaming and opportunities (i.e., volunteering as a service or giving back) ➢ A safe, healing and welcoming space* ➢ CARE training (Competencies in Awareness, Respect and Empathy) ➢ The history of the HIV movement and/or PWA ➢ Personal journey **how you define this is up to you*	
7	Take a photo that shows what is missing from our conversations. What are we not talking about?	